

**THE ATTITUDES OF PRIMARY CAREGIVERS
TOWARDS
CARING FOR HIV/AIDS ORPHANS.
IN THE
INGWAVUMA DISTRICT**

NOKUTHULA VERONICA GUMEDE

2003

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IN THE
INGWAVUMA DISTRICT**

by

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for the Degree of

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Supervisor: Prof TAP Gumbi

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DECLARATION

I, NOKUTHULA VERONICA GUMEDE, declare that the research study on "The Attitudes of Primary Caregivers towards caring for HIV/AIDS Orphans" is my own work and that all sources I have used, have been indicated and acknowledged by means of complete references.



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**NOKUTHULA VERONICA GUMEDE**

Date: September 2003

## **DEDICATION**

This work is dedicated to my loving husband, DECEMBER MUSA GUMEDE, my brother-in-law, B.M. Gumede, to my parents, to my three sisters Nozipho, Zodwa and Dudu and to my four children Lethukuthula, Nomfundo, Gcinukuthula and Khethukuthula, for their love, support and encouragement throughout my studies.

## **ACKNOWLEDGEMENTS**

I would like to express my sincere gratitude and appreciation to the following people, who have contributed to the success of this study.

1. My Supervisor, Prof T.A.P. Gumbi, for his professional guidance, encouragement and support.
2. To my family members, brothers and sisters.
3. Colleagues at work, Ms H.G. Dubazane, Mr T.C. Nyawo, Mr N.P. Ngubane and Mr B.E. Xulu for their support and encouragement.
4. The academic staff in the Social Work Department at the University of Zululand.
5. To all the respondents of my study for their co-operation.
6. To Nokukhanya Mthembu, for typing this work.
7. Above all, I would like to thank God who always strengthened me in everything I do, whom also made it possible for the abovementioned people to make suggestions out of their willingness to make this work a success

KwaDlangezwa

September 2003

## **ABSTRACT**

This study is about the attitudes of primary care givers who are caring for HIV/ AIDS orphans in the Ingwavuma area. As an evaluative research semi-structured interviews were conducted. A sample of twenty primary care givers was drawn, 10 files were drawn from the Department of Welfare and Population Development Office and 10 files were drawn from the local non-government organisation called Ingwavuma Orphan Care. Permission to use departmental files was sought from the department concerned.

Related literature that focuses on a HIV/AIDS and Orphanhood has been reviewed. Various recommendations have been made based on the findings of the study.

The findings indicate that a need exist for training on parenting and coping skills. HIV/AIDS orphans need to be involved in counselling especially on trauma counselling, this can help a lot in improving the relationship between primary care givers and vulnerable children.

## **OKUFINGQIWE**

Lolu cwaningo lubheka indlela ababheki bezingane ababheka ngayo abantwana abakhungethwe isifo sengculazi.

Kulolu cwaningo kwaba nemibuzo ehleliwe eyayibhekiswe kubabheki bezintandane abangamashumi amabili. Amafayela alishumi atonyulwa ehhovisi loMnyango wezeNhlalakahle, nokuthuthukiswa kwesintu elinye ishumi lamafayela latonyulwa enhlanganweni ezimele ebizwa ngokuthi "Ingwavuma Orphan Care". Imvume yokusebenzisa lamafayela yacelwa eminyangweni efanele.

Kubhekwe imibhalo egxile kakhulukazi kulo igciwane lengculazi kanye nobuntandane. Kube nezincomo ezahlukeni ezenziwe zisuselwa emiphumeleni yocwaningo.

Imiphumela yocwaningo iveze ukuthi kunesidingo sokuba kuqeqeshwe ababheki bezintandane mayelana nokuphatha lababantwana njengabazali babo kanye nendlela yokumela isimo esinzima. Izintandane nazo zimelwe ukuba ziqeqeshwe nazo zisizwe, zinikwe amaqhinga okwazi ukuzimela nokumela isimo esibucayi nesinzima. Lokhu kungasiza ekuthuthukiseni ubudlelwane phakathi kwezintandane nabo singamzali. Nalabo abazibhekayo.

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# **CHAPTER ONE**

## **ORIENTATION TO THE STUDY**

### **1.1 INTRODUCTION**

Stigma and discrimination around HIV/AIDS infection remains a major challenge. The government has a crucial role in ensuring that children, families and communities are coping with HIV/AIDS orphans. In addition, the HIV/AIDS epidemic, the government needs to further develop and reinforce laws and policies to protect the increasing number of vulnerable children. Its response to children affected by HIV/AIDS must be multisectoral and integrated with basic health, education and developmental programmes. South African communities are confronted with a vast number of social problems including caring for HIV/AIDS orphans, which results in poverty in most of the families.

### **1.2 STATEMENT OF THE PROBLEM**

The HIV/AIDS pandemic affects everyone, families, organizations and every business whether big or small. It poses greater challenges in the family. The condition of children affected and infected by HIV/AIDS pandemic is fast approaching a human catastrophe of immense proportions. This exerts great pressure on the family, especially the extended family, which has been left with the burden of caring for the orphans. Because of the magnitude of the problem the researcher felt, it is important to conduct a study on this issue.

### **1.3 MOTIVATION FOR THE STUDY**

The researcher's motivation emanates from being involved in caring and counseling the orphans and their primary care givers at Ingwavuma. It has been observed that the number of orphans in Ingwavuma District is escalating especially the child headed households. This led the researcher to investigate an attitude of primary care givers towards caring for HIV/AIDS orphans and to determine the availability and the extent in which the extended family provides support.

### **1.4 HYPOTHESIS**

The following is the hypothesis of the study.

Most orphans receive less support from their extended families because of the following reasons:

- High level of ignorance and attitude toward HIV/AIDS sufferers.
- Certain entrenched cultural perceptions about people who have died of HIV/AIDS.
- The stigma attached to HIV/AIDS.

## **1.5 OBJECTIVES OF THE STUDY**

The objectives of the study are as follows:

- To ascertain whether the resources provided by the government are meeting the identified problems of orphans and their care givers.
- Provision of strategies by government.
- To suggest strategies that can be implemented in addressing identified problems through resource mobilisation.

## **1.6 RESEARCH METHODOLOGY AND PROCEDURE**

The design and methodology of the study are discussed as follows:

### **1.6.1 Research design**

A research design provides the answer to a question: "What are the means to be used to obtain the information needed? (Mouton and Marais, cited by Collins in McKendrick 1987:260). The researcher used both the qualitative and quantitative methods of research. It is the overall plan or strategy by which questions are answered or hypotheses tested (Reid & Smith, cited by McKendrick 1990:256).



According to Newman (1997:30) "quantitative data method refers to the collection of data using number counts and measures of things and qualitative research basically, which involves the use of words, pictures, descriptions or narrative."

In this study the researcher used the descriptive design. The object of this design is to reveal potential relationship between variables. It includes both qualitative and quantitative descriptions of the phenomenon under investigation (McKendrick 1987:257).

### **1.6.2 Population and sample**

The research population comprised of the primary caregivers who care for HIV/AIDS orphans in Ingwavuma District. The researcher interviewed the primary caregivers that are caring for HIV/AIDS orphans. In choosing the respondents the researcher used the probability sampling procedure. Systematic random sampling was carried out where ten (10) files were randomly selected from Social Security files in the Ingwavuma Department of Social Welfare and Population Development and ten (10) names were drawn from the list of orphans in Ingwavuma Orphan Care Office. The total number of twenty (20) respondents were included in the study.

McKendrick (1993:269) states that probability sampling ensures all elements of the population have a known chance of selection.

### **1.6.3 Research instrument**

An interview schedule was used which enables the researcher to probe both verbal and nonverbal cues of the respondents and this gave the interviewer the opportunity to clarify matters where necessary. The researcher used an interview schedule which comprised both open and close-ended questions. The interview schedule was constructed in English and then translated into IsiZulu and administered in the same language, IsiZulu, as almost all the respondents have a low educational standard, and therefore are not conversant with English.

### **1.6.4 Procedure for data collection**

The researcher selected the structured interviews as a method of collecting data. The researcher perused project documents of previous studies; project reports for NGO's and other articles related to HIV/AIDS orphans. The interview schedule was used which had fixed response questions and open-ended questions.

### **1.6.5 Data analysis and interpretation**

The information gathered were statistically analysed using graphs and tables in presenting data. The findings were presented in the form of descriptive statistics and qualitative discussion of findings.

## **1.7 DISSEMINATION OF THE STUDY**

The information will possibly be published in the following:

- Welfare newsletter
- Social Work journals
- Government articles
- Copy will be referred to the university library.

## **1.8 VALUE OF THE STUDY**

The study is aimed at assisting policy makers in improving the present welfare policy relating to the care of HIV/AIDS orphans.

## **1.9 DEFINITION OF TERMS**

The following terms are defined in order to eliminate misunderstanding about the conceptualisation of terms.

### **1.9.1 Attitude**

Thrasher *et al.* (1990:19) define an attitude as certain perspectives or ways of viewing things, which then become natural antecedents to certain behaviour or certain emotional responses.

### **1.9.2 Primary caregiver**

"Primary caregiver is often the mother, grandmother or relative of the family who has to carry a huge burden of looking after orphaned children. Not only that; she or he has to look after a sick and dying person, but she or he also has to ensure that life goes on for the ones living in her home" (Van Dyk 2001:332).

### **1.9.3 Child**

According to the Child Care Act No. 74 of 1983 a child is any person under the age of 18 years.

A child in this study could be viewed as any person under the age of 21 years.

### **1.9.4 Orphan**

"An orphan is a person, especially a child, whose parents are dead" (Oxford Dictionary 1975:721).

In this study an orphan could be viewed as a child who has lost both parents.

### **1.9.5 Foster care**

"Foster care means the placement of a child with a non-relative after careful selection of the family. The selection process should take factors such as the traditional cultural background, norms and values of the child and the foster family into account when trying to make a match. Families who foster children usually receive a small foster grant from the government to assist them with some of the costs involved in caring for another child" (Van Dyk 2000:335).

### **1.9.6 Human Immuno Deficiency Virus (HIV)**

HIV stands for "human immuno deficiency virus," "human" because the virus causes disease only in people, "immunodeficiency" because the immune system which normally protects a person from disease becomes weak, "virus" because like all viruses, HIV is a small organism that affects living things and uses them to make copies of itself (Granich & Mermin 1995:5).

### **1.9.7 Acquired Immuno-Deficiency Syndrome (AIDS)**

Acquired Immuno-Deficiency Syndrome known as AIDS is a group of diseases that occur when a person's immune system is damaged (Granich & Mermin 1995:5).

## **1.10 PRESENTATION OF THE STUDY**

This study will be presented as follows:

Chapter 1: Orientation of the study

Chapter 2: Historical background of the area

Chapter 3: Literature review

Chapter 4: Research design and methodology

Chapter 5: Findings of the study

Chapter 6: Conclusion and recommendations

Bibliography

Appendix A: Interview Schedule

(a)(i) IsiZulu

(b)(ii) English

Appendix B: Map of the area

## **CHAPTER TWO**

# **THE HISTORICAL BACKGROUND OF INGWAVUMA AREA**

### **2.1 INTRODUCTION**

This chapter deals with the history of Ingwavuma area in northern KwaZulu-Natal. It looks at the demographic profile of the population density and the estimates of AIDS orphans. It explains the various programmes, which are rendered by various institutions in trying to assist those who are affected or infected by HIV/AIDS.

This chapter is also aiming at determining the availability of external support to families who are affected by the HIV/AIDS pandemic.

### **2.2 THE HISTORICAL BACKGROUND OF INGWAVUMA AREA AND ITS ORIGINS**

The Ingwavuma district is a rural area lying to the north of KwaZulu-Natal. It is bordered by Swaziland to the west, Mozambique to the north and the Pongola River to the southeast. The area is far from urban areas. It is approximately 500 kilometres north of Durban metropolitan area. Durban is the main city, commercial and industrial centre of the province of KwaZulu-Natal. Ingwavuma covers some 2,100 kilometre square and has an estimated population of 675 188. The terrain consists of Lebombo Mountains in the north and Pongola flood plains in the east.

Homesteads are scattered over the whole district without formalized grouping in the way of villages. The area is divided into two parts, i.e., it consists of the Upper and Lower areas. On the Upper part, there is Ingwavuma village; at the Lower part there is Ndumo village. There is high concentration of homesteads around these villages, which has a small shopping centre, a post office, Ithala Bank and government buildings. The majority of the people live in remote homesteads about a hundred metres away from the nearest road. People of this area survive through subsistence farming, migrant labour benefits and government grants, i.e., Old Age Pension, Disability Grants, Child Support Grant and Care Dependency Grants. The living conditions in this district are basically rural and most communities experience problems related to the lack of basic amenities such as water, electricity, telephones and roads. Although the main road is tarred, many other roads are gravel.

There are limited employment opportunities in the area, and most of the working population consists of migrant workers. The area is known for its beautiful vegetation. The main vegetation is of trees and these trees are mainly used for firewood, building huts, fencing gardens and for warmth. Poverty is rife as there are no factories or industries where local people could be employed. As a result most men had to migrate to cities like Johannesburg and Durban to look for work, especially in the gold mines. Women are always left alone to maintain the families. Most of the households are headed by women. Cultural beliefs are still observed. For example, polygamy is still practised in most of the households.

AIDS is also prevalent in the area. The impact of this pandemic plays a tremendous strain on the family and the community. Although the extended family still plays a vital role in nurturing the family members, there are indications that the integrity, cohesion capacity and efficiency of the extended family as a support system is being undermined by social upheavals, i.e., rapid



death of most of the community members, relatives and friends, poverty and over-stretched resources.

In Ingwavuma the number of children orphaned by AIDS is escalating and this has become a social problem. Over the years the extended family system used to meet most of the social and emotional needs of children including orphans. It provides a protective social environment in which children grow and develop. As poverty and unemployment is prevalent in the area most families are not coping with the burden of supporting the orphans placed in their care. The women who suffer the most, as they have to take care of their dying sons and daughters-in-law.

Grandparents and teenagers are now heading most households. It has been observed that the family structure and care-giving patterns have changed. The burden of care now falls on those who have the least capacity to provide parenting support and care for the affected children. The burden is now on the shoulders of the elderly and the young.

### **2.3 PHYSICAL CHARACTERISTICS OF THE AREA**

The land is owned and used by community members. It is still under the control of traditional leaders. People own and control the physical resources of the area. The land is used mainly for subsistence farming. As Ingwavuma is divided into two sections, i.e., Upper and Lower Ingwavuma, Upper Ingwavuma is mountainous and down in the low veld is flat.

Community members use bakkies, buses and mini-buses. In other inaccessible roads they use 4x4 bakkies for transport. There are adequate telephone booths around highly populated areas like Ndumo, Ingwavuma, Manyiseni and

Bhambanana. Community members need to travel for about four kilometres in order to access phones. In those areas where one finds a telephone booth, one finds that it has been vandalised. The areas need to be developed as it is still very rural and remote and largely not caring for facilities provided such as telephones.

## **2.4 POPULATION DENSITY**

The area is along the border with Swaziland and Mozambique. The location of the area results in having unrealistic statistics. The population density is incongruent with the area since most community members hold dual citizenship South African and Swazi. They visit relatives in Swaziland and their relatives visit them as well. They come and go out of the country and this also has an impact on the spread of the AIDS virus. The population of this district is believed to be 675,188. The number of households is 93,643 (Investment Opportunities in Umkhanyakude District Municipality).

## **2.5 TRADITIONAL LEADERSHIP**

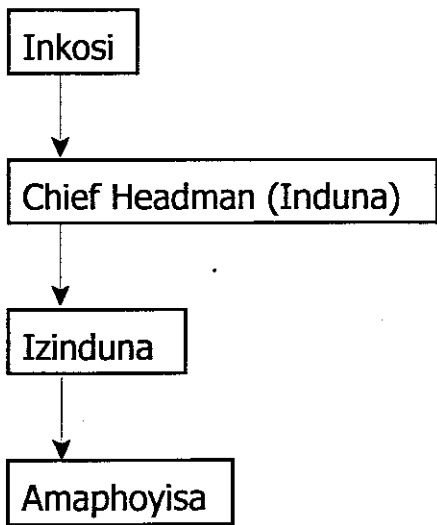
There are three Tribal Authorities, i.e., Mathenjwa, Nyawo and Mngomezulu. These cover the jurisdiction of the Ingwavuma district. Laws and issues relating to the development of the area are still controlled by these tribal courts. Quarterly meetings called "Nyangantathu" are held where resolutions and issues, which have been discussed at the local tribal courts, are further discussed. The councillors report to the traditional leadership as well as to the local Municipality, i.e., Jozini Municipality Local Government, Umkhanyakude District Municipality, a Zulu name for a tree which is commonly known as 'fever tree'. It literally translates into "that shows light from afar." This municipality is known for its geographical location, which gives it a unique cultural diversity, and it is also

known for its beautiful vegetation. The izinduna only reports to their traditional leadership, i.e., Inkosi. They only report to the municipality if a need arises.

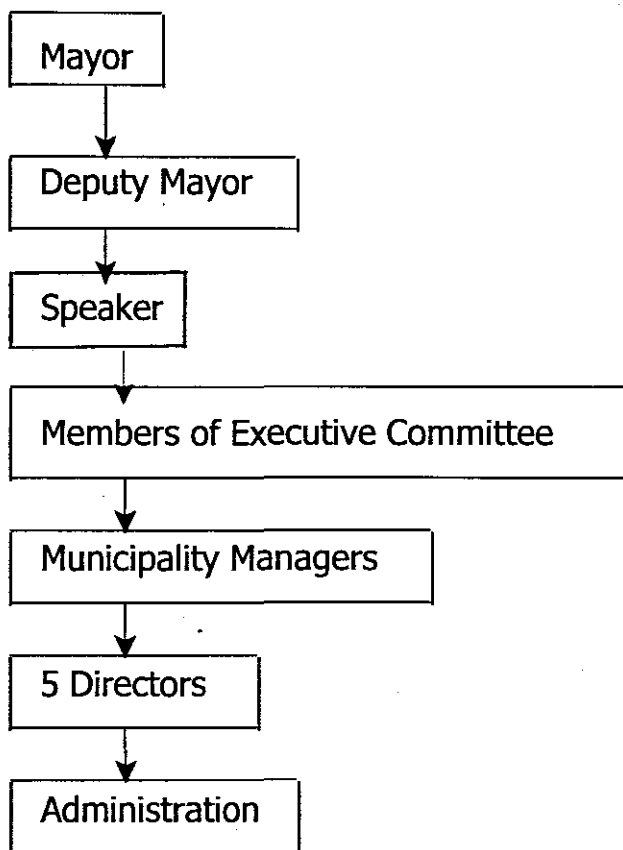
**2.5.1 The structure of the Traditional leadership**

Traditional leaders implement government policy and enforce the law whilst the municipality implement government policy and see to it that development takes place in their respective areas.

There are four tribal authorities in the area, i.e., Nyawo, Mngomezulu, Tembe and Mathenjwa Tribal Authority. Each Tribal Authority is represented by Inkosi; who is responsible for the management of the tribe. There are various areas (izigodi), the Induna is responsible for the areas under his jurisdiction.



**2.5.2 Structure of the Umkhanyakude District Municipality**



**2.6 HIV/AIDS SUPPORT PROGRAMMES FOR THE INGWAVUMA DISTRICT**

There are various support systems for community members. Different departments and non-government organizations are involved in assisting families and children who are affected or infected by the disease, HIV/AIDS. They assist communities by empowering them with different skills and knowledge so that they can be in a position to cope with the stressful situation that they find themselves in.

The Departments of Health, Welfare, Education and Agriculture try to assist communities in dealing with the appalling situation that they find themselves in.

Many programmes in this district have been initiated by the Department of Health; hence they are strongly linked to the Hospital, i.e., Mosvold Hospital, thus facilitating co-operation and sharing of information.

## **2.7 MOSVOLD HOSPITAL AIDS ACTION TEAM**

Mosvold Hospital has 246 beds. It is situated in Ingwavuma Village. This hospital has an AIDS Action Team, which was initiated in 1990 and has long been aware of this pandemic. The hospital has a residential clinic and 30 mobile clinics. The HIV/AIDS pandemic has now reached a mature phase, as a result the AIDS Action Team has shifted its role from prevention and counseling to that of caring for the dying patients and orphans that have been left behind by their parents. There is another model which has now been established which is called the home base care. The home base care is the provision of comprehensive services, which includes health and social services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximal level of comfort, function and health, including care towards a dignified death.

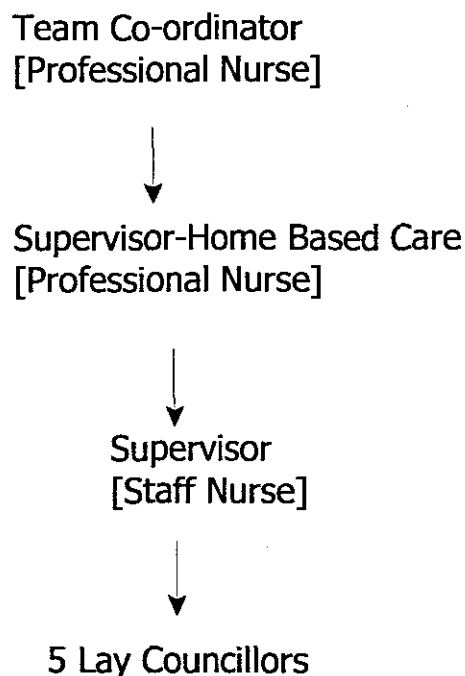
The main objective of home-based care is to ensure that children and families who are orphaned by HIV/AIDS, have access to social welfare services within their communities. This model which is used by the Mosvold Aids Action Team aims at ensuring that persons who are infected and affected by HIV/AIDS have access to integrated services that address their basic needs for food, shelter, education, health care, family or alternative care and protection from abuse and maltreatment. The AIDS Action Team is faced with the growing number of people who are dying of this disease. As a result there is many orphans in the area. This has resulted in the development of an NGO called Ingwavuma Orphan Care, which was initiated to help orphans, in their plight of losing parents.

The Mosvold AIDS Action Team has also a programme for the people living with AIDS [PWA]. Groupwork sessions are held with this group. The challenge now facing the Mosvold AIDS Action Team is the increasing number of people living with AIDS which. The group members are reluctant to part with the big group as they allege that if they terminate their membership with the big group they are going to be discriminated against in their own communities.

There is also another programme that is run by this team, the administration and supervision of Voluntary Counseling Testing (VCT). Volunteers run this programme, i.e., they counsel patients and administer voluntary testing.

### **2.7.1 Structure of the Mosvold AIDS Action Team**

The structure of the Mosvold AIDS Action Team stands as thus:



Source: Mosvold Hospital staff establishment  
There is good working relationship with the Mosvold Hospital AIDS

Team and the rest of the Hospital staff. After a patient has been identified either at the Outpatients Department (OPD) or by the Community Nurse or Mobile Clinic Team the patient is referred to the AIDS Action Team for counseling and further monitoring.

## **2.8 INGWAVUMA ORPHAN CARE**

Ingwavuma Orphan Care originated out of the work of the AIDS Team at Mosvold Hospital. It is a non-profit organization. It was started in 2000 as a joint venture between the Departments of Health, Welfare and Agriculture. The need to establish this programme separately was promoted by the number of orphans, which was escalating, and after the recognition by other stakeholders that this is not only a "health" issue. AIDS falls also under the purview of other departments. The primary goal of the programme is to secure a sustainable lifestyle of dignity, hope and opportunity for the orphaned families in the Ingwavuma district. This will entail working towards the delivery of statutory assistance to the families, enhancing their life opportunities through education, life skills training and mutual support at orphan club days.

The organisation also tries its best to help orphans who are living in the community to access government grants, payments of school fees, providing them with food and clothing. It also identifies child headed households. The structure of this organisation stands as follows:

## **2.9 NDUMO RESOURCE CENTRE**

Ndumo is the area under Ingwavuma district. It lies on the border of Mozambique. About 21,000 people live in the area and most of the residents survive by subsistence farming. Employment in the area is from the game park,

schools, a few shops and a clinic. The people from this area are some of the poorest in KwaZulu-Natal and their lives are made more difficult by the high rate of malaria, TB and AIDS (Barnard 2002:18).

Mosvold Hospital AIDS Team established the Resource Centre in 1998. It is housed in the property owned by the Roman Catholic Church. The centre acts as a resource and an education point for the local community. The members of the centre are also involved in various activities like sewing, juice making, baking, barbed wire making, knitting, grinding maize-meal milling and gardening. The centre has a video machine and a cassette player. These are for educational purposes only. The staff at the centre is trained to talk openly about AIDS. Training workshops are run in the centre and home visits are undertaken from the centre to assist those who are terminally ill and those who have been infected or affected by HIV/AIDS.

Presently there are four Community Home-based Care Workers who were trained from November 2000 to January 2001 and they started working in February 2002. This programme provides support to people dying of AIDS at home.

## **2.10 SINAKEKELISIZWE NETWORK**

This is a non-profit organization. Its main aim is to network and to tap for funds for all the programmes under the Umkhanyakude or DC 27 district. It is formed out of the five hospitals of Umkhanyakude or DC 27. These hospitals are Hlabisa, Manguzi, Mosvold, Bethesda and Mseleni. There is only one Project Co-ordinator who is operating from Bhambanana Flagship Project, which is a project run by unemployed women with children under the age of 15 years. This project is situated at the T-junction road to Ingwavuma and Manguzi.



It is under the supervision of the Department of Social Welfare and Population Development, Ingwavuma district. All Orphans Care Projects and Resources Centre under Umkhanyakude affiliate under the Sinakekelisizwe network.

## **2.11 THE ROLE OF LOCAL CHURCHES**

Churches play a very important role in caring for orphans. They cater for the emotional psychological and material needs of orphans. Through the church, it is where the vulnerable families especially child headed families, get comfort and care.

There are different types of church denominations existing in the area. These include the following:

- The Anglican Church
- The Roman Catholic Church
- The Methodist Church
- The Dutch Reformed Church
- The Seventh Day Adventist Church
- The African Evangelical Church
- The Evangelical Church
- The Zion Congregational Church (ZCC)
- The Nazareth Church
- The Zionist Church
- The Maranatha Church
- The Christian Centre
- The Apostolic Faith Mission
- The Faith Mission
- The Church of Christ; and
- The Church of the Holy Ghost

## **2.12 SIBAMBISENE FORUM**

Sibambisene is a non-profit organisation. It is an organised structure that provides an opportunity for networking communication and intersectoral collaboration. Its main objective is to enable all stakeholders to co-ordinate all activities that take place in DC 27. This is done to avoid duplication. It consists of representatives from each government department, non-governmental organizations and Community-based Organizations. All HIV/AIDS activities undertaken in DC 27 need to be known to the Sibambisene Forum.

## **2.13 SOCIAL PATHOLOGY IN THE AREA**

The community is wide with a high population living in close proximity. This area is very rural and remote. The residents are very poor and the majority of the residents live on state grants, that is, disability grants, child support grant, foster care grant, care dependency grant and old age pensions.

The most significant employer in the area is the government. The poverty rate for rural areas is 71%, 3 out of 5 children live in poor households and bear the brunt of poverty, being exposed to malnutrition, domestic violence, inconsistent parenting and schooling thus promoting the impact of the AIDS pandemic (McLaren 2002:vii).

The living conditions in this district are rural and the population experiences problems related to the lack of basic amenities such as water, fuel, electricity, telephones and roads. Water is drawn from taps, rivers, pans and occasionally wells.

There are limited employment opportunities in the area. People survive on subsistence farming. Unemployment is a social problem in this district. It is rated at  $\pm 70\%$  (Report on Investment Opportunities in Umkhanyakude District 2002).

#### 2.14 **SUMMARY**

The area is characterised by social ills which have a past history of neglect and backwardness. The government of national unity is addressing the problem of unemployment in the area and making sure that services is rendered efficiently in that community. HIV/AIDS becomes the priority and there are now programmes that are being initiated to alleviate this social problem. This chapter has attempted to give an overview of the history of the Ingwavuma area.

# **CHAPTER THREE**

## **THE ATTITUDES OF PRIMARY CARE GIVERS TOWARDS CARING FOR HIV/AIDS ORPHANS IN INGWAVUMA DISTRICT**

### **3.1 INTRODUCTION**

"HIV/AIDS is having a divesting impact on the world's youngest and most vulnerable citizens. One of the most telling and troubling consequences of the epidemics is the growing number of children it has orphaned or seriously impacted. Today more than 13 million children currently under the age of 15 have lost one or both parents due to AIDS (Children on the Brink 2002:2). The women who suffer the most, are those who have to take care of their sons and daughters in-law.

The number of children orphaned by AIDS is increasing at an alarming rate and this is becoming a serious problem. Over the years, societal structures such as the extended family have met most of the social and emotional needs of children, including orphans and provided a protective environment in which they could grow and develop.

### **3.2 CHANGING FAMILY STRUCTURE AND CARE GIVING PATTERNS**

In the countries hardest hit by HIV/AIDS care for orphans and children affected by HIV/AIDS lies primarily with their families and communities. AIDS is placing a huge burden on the extended family sub-system, "the backbone of African

societies," while also ravaging entire communities. This leaves many orphans with little support (Children on the Brink 2002:2).

In the African culture it is the responsibility of the extended family to care and provide support to the children of the deceased family member. The capacity of families to absorb the escalating numbers of HIV/AIDS orphans is gradually diminishing.

"Extended families take in the overwhelming majority of orphans who lose both parents. But in many cases, orphaned siblings are sent to different households and experience a second profound loss, through this HIV/AIDS leads to the financial vulnerability of individuals and families. It creates additional costs, which may place households under great financial strain. Apart from the financial stress, children suffer the death of one or both parents and parents lose their adult children. Grandparents and elderly relatives increasingly have to take responsibility for orphans and caring for sick adult children" (White Paper for Social Welfare No. 18166, 8 August 1997:89).

Caring for the sick is causing an emotional stress to the elderly relatives. HIV/AIDS is causing the most significant changes in the family sub-system.

These days people plan their families and are generally unwilling to have to feed an extra mouth, even those who do not bother about family planning are reluctant to accommodate outsiders (A study into the situation and special needs of children in Child Headed Households, June 18, 2001:35).

The death of both parents of a young family is a major catastrophe for the children. It is now left on the extended family to decide as to which family member will assume responsibility over the children (Children on the Brink

2002:9). Children are the ones who experience trauma after the death of their parents.

McKendrick (1987:14), outlined

“that difficulties experienced by families may arise within the family and may have their sources in the natural course of events in human and family life cycles. These lifestyles alter roles and behaviour of family members when new roles and strategies are developmentally assigned to them, which in turn necessitate the acquisition of new life skills.”

The researcher also supports McKendrick (1987:14), which HIV/AIDS causes a lot of stress in the family. The family structure and roles have to change, as the family, which has always been a small family has to accommodate more family members.

Women's roles as primary care givers may radically transform as they find themselves with less time for other family members, friends and with the demands of new children interfering with their ability to give the quality and quantity of instrumental assistance they formally may have been providing for an elderly parent a neighbour or their own children.

Caring for an orphan changes the care giving patterns of the primary care givers as she has to concentrate more on caring for the new family member.

### **3.3 STIGMA AND DISCRIMINATION**

“AIDS influences human dignity because infection with the disease goes hand in hand with stigmatisation and discrimination. These symptoms of this disease are

frightening, knowledge about HIV/AIDS is limited and the mode of transmission is associated with socially unacceptable behaviour. The result is a negative social response. This renders AIDS a perfect paradigm for stigma, because it is associated with unsanctioned behaviour such as sex workers, multiple sex partners and gays, although AIDS is mainly a heterosexually transmitted disease in Africa. Misconceptions about its spread add to the stigma" (De Beer & Swanepoel 2000:204). Stigma associated with AIDS is still a problem in most communities.

"HIV/AIDS related stigma and discrimination is wide-spread in Africa as in other parts of the world, such stigma results in rejection, denial and discrediting and consequently leads to discrimination which inevitable frequently leads to the violation of human rights, particularly those of women and children" (Advocacy for Action on Stigma and HIV/AIDS in Africa, June 2001:1).

It would seem therefore, that stigma and discrimination around HIV/AIDS remain a major challenge. A person who is HIV positive is usually frowned upon by the community as well as by other community organizations especially the church. Communities still have negative attitudes towards the infected and the affected person.

Our government has promised in our Constitution and by signing the United Nations (UN) Convention on the rights of the child that all children have a right:

- To life and so their basic physical needs must be met such as food, shelter, clothing and clean water.
- To health care and treatment when ill or hurt

- To the love, protection and care they need to be safe and healthy
- To education including the right of older children to training that will help them to earn an income
- To participate in decisions that affect them according to their age and capacity .
- To grow up to be responsible and caring members of society and should have loving care guidance and education from parents, care given or parent figures
- To play, recreation and to participate in cultural activities
- That children in difficult circumstances need special care. Those who are orphaned have a right to be placed in alternative family care. Children who live with a disability and those who have a chronic, ongoing, illness also has special needs and rights (Community Help for Children living in an HIV Positive World 2002:13).

"The AIDS epidemic has created more than 13 million orphans (children under the age of 15 years who have lost a mother or both parents to AIDS) and 95% of these children live in sub-Saharan Africa. Because the extended family system (which would have traditionally provided support for orphans) is greatly over extended in those communities most affected by HIV/AIDS, it can now no longer take care of its orphaned children. The stigma associated with AIDS deaths in many communities contributes to the fact that many families do not want to look after AIDS orphans" (Van Dyk 2001:334).



AIDS orphans are not treated like orphans whose parents have died of other causes. They are rejected and isolated by the family and by the community at large.

### **3.4 PERCEPTION OF ILLNESS IN TRADITIONAL AFRICA**

Africa has so many AIDS patients that hospitalization is not always an option. The enormous need for care leaves the community with no other choice than that they should care for their own sick. At the family level, the burden of care is predominantly borne by women and girls. Men are also increasingly willing or forced to care for sick partners. However, the least acknowledged primary care givers within the home are the children. When one parent dies, there is often no one else to look after other parent when he or she falls ill (Van Dyk 2001:112). Women are regarded as the cornerstone of the nation, so the burden of care always lies with them.

In some cases both parents die resulting in the eldest child, caring for his or her younger brothers and sisters. Hence we have households headed by adolescents (sometimes as young as 12 years old) who are caring for their younger siblings. If these children cannot be accommodated in foster care programmes, community (and government) support should be offered to help these children to cope with their plight (Van Dyk 2001:337).

"If something bad happens to traditional African society, he or she will not attribute such an event to bad luck, chance or fate. They believe instead that every illness has been directed by an intention and a specific cause, and in order to fight the illness, it is necessary to identify, uproot, punish, eliminate and neutralise the cause, the intention behind the cause and the agent of the cause and intention. As they attempt to understand an illness, traditional Africans will

always ask the questions "why" and "who" (Van Dyk 2001:112).

In a traditional family if a family member is sick there is always a cause for his illness. Somebody in the community or in that family has bewitched that member of the family. Traditional healers are widely consulted throughout Africa. Their problem is that their importance within communities is not officially recognised; hence they care for people with HIV/AIDS without support from the formal health service sector.

"It could be observed following from the above that, secrecy and fear of disclosure among the family members make the task of caring for AIDS orphans very difficult. If they are supposed to keep the HIV positive diagnosis a secret family care given often find it difficult or impossible to seek help from outside. Caregivers from outside the family cannot easily pass on knowledge or health care skills to the family members if the family members do not know that the patient has AIDS. The outside caregiver must thus carry the responsibility alone. It is also impossible for the care giver to prepare the family for the death if the AIDS diagnosis is a secret" (Van Dyk 2001:284).

### **3.5 AIDS AND POVERTY**

HIV/AIDS leads to financial vulnerability of individuals and families. They often lose their formal sector employment, which can affect the entire households if the person is the key breadwinner with dependents in rural areas. HIV/AIDS creates additional costs, which may place households, which are indirectly affected by the death or illness of a person with HIV/AIDS. They feel this strain, for example, families who receive orphans or who are involved with care giving of some sort (a study into the situation of Child Headed Households, January 2001).

While many families appear to be willing to care for the AIDS sick and to nurture and socialise orphans, some are not able to do so owing to financial strain, poor living conditions or the absence of close relatives to provide the necessary care and support. Families in rural communities are severely affected as welfare and social services in these areas are particularly underdeveloped (White Paper for Social Welfare, 8 August 1997:89).

"It is argued, therefore that, in order to determine the link between HIV/AIDS and poverty, we should start with the link between health and development. Healthy individuals can work harder and be more productive, they perform better at school and university and they earn more than those who are unhealthy. Valuable resources are spent on health care when people are unhealthy, which could be used for community development instead. Human dignity is also enhanced when people are healthy. On these grounds alone one can say that AIDS will have a profound impact on development, because when people contract HIV and AIDS they become economically inactive in time and an economic and social liability in the final stage of the illness (De Beer & Swanepoel 2000:200).

HIV/AIDS has an impact on the family. In the family more time and money are spent on caring for persons suffering from AIDS. This leaves less time to earn money, resulting in fewer resources to care for the household, with the added burden of money to be spent on medical care for the infected person. To pay for this care, people may be forced to sell their land or livestock, make withdrawals from their savings or borrow from others, which will burden the already weak household. When the infected person eventually dies, funeral costs are added to this burden (De Beer & Swanepoel 2000:201). HIV / AIDS has a negative impact on the family sub-system.

### **3.6 CHARACTERISTICS AND ATTITUDES OF PRIMARY CARE GIVERS**

Costin (1972:345) states "foster parents are generally recruited from lower socio-economic groups. They are persons with minimal education, are older than the foster children's own parents and often live in rural or suburban areas quite distant from the social and health resources of metropolitan communities. They frequently show strikingly ambivalent or rejecting attitudes towards disturbed children they care for, some foster parents have been found to be more authoritarian in child rearing than other parents and to hold social attitudes usually labeled as economic or pathogenic.

Their lack of empathy or understanding of the problems of their foster children often retard or prevents successful therapeutic efforts on their behalf. They show confusion or lack of clarity about their role and paucity of knowledge about child behaviour, and they lack constructive techniques use in child rearing."

She further observes that the family is the most important institution in the life of a child. Placement of children in a family gives the child a chance to form emotional relationships to substitute parents and the rest of their family members, their friends and neighbours.

"It is therefore observed that, controlling children other than ones own is apt to produce special problems especially if their behaviour is demanding, aggressive or otherwise troublesome. Primary care givers may find themselves plagued by doubts about their usual methods of discipline and uncertain about action to take in behaviour control (Costin 1972:339).

Taking care of children other than your own places a great pressure on the one who is taking care of those children. It is a big challenge to the primary care giver.

A child, who is removed from the care of his or her parent and placed in alternative care, normally undergoes a distressing and painful experience. Feelings of abandonment and helplessness are common, each child will react differently to the removal and feelings aroused will depend on factors such as age, the nature and extent of the relationship with the primary care giver and the child's ability to understand what is really happening to him or her.

The following are some feelings and reasons, which may be present in varying degrees in different children during the process of removal and placement:

- A child experiences insecurity as a result of the loss of a parent.
- The lifeline of a developing child is broken prematurely as his or her natural sense of belonging is lost.
- A child's self image is seriously impaired through lack of identification with his or her own parent.
- A child is likely to go through the phases of protest, despair and detachment.
- A child may experience difficulties to adjust to the unfamiliar placement in a foster home (Information Guide for Social Workers on the Practical Application of the Child Care Act No. 74 of 1983, as amended and Regulation 1998:7).

When people apply to give care, the agency must determine how suitable they are to the task of caring for children other than their own. An initial screening usually occurs. The agency makes an early assessment of tangible qualities such as the age and health of the family members, and the suitability of the location of their home, its space and other physical factors such as cleanliness and sanitation. In turn the prospective foster parent's make an early judgement as to whether they can meet the agency's requirements and work with the agency's representative in relation to the characteristics and needs of the children reported to them as needing placement (Costin 1972:348).

The placement of children must be a voluntary decision by foster parent or a primary care giver. The age and health status of both the prospective foster parent and the child must be taken into consideration.

### **3.7 SUPPORT NETWORKS AND SOCIAL SUPPORT**

According to Minkler and Roe (1993:99), people need to be healthy. Both social networks and the web of interpersonal relationships in which individuals are embedded and the supportive resources they give and receive through those networks' bear an important relationship to health and well-being. The presence of social ties and social support has shown to protect people in crisis from a wide variety of pathological states to increase recovery rates from illness and to affect self-esteem and life satisfaction positively.

Being a member of a certain institution, sector, or body makes one to have a sense of belonging and to cope with whatever stress that comes on his or her way.

There are various types of resource systems, which people rely on when they are in trouble. Pincus and Mineham (1983:3) mentioned that people depend on a support system for help in obtaining the material, emotional or spiritual resources, the services and opportunities they need to realise their aspirations and to help them to cope with their life tasks.

They further state that people can find help from two kinds of resource systems:

- Informal or natural resource system which consists of the family, friends, neighbours, co-workers and helpers
- formal resource systems which are membership organizations or formal associations which promote the interest of its members.

Through public activities and voluntary citizens action society has established a great variety of societal resource systems. People become linked to several of these systems, some such as hospitals, adoption agencies, vocational training programmes and legal services that are designed to meet the short term or special needs.

Primary care givers may depend on these systems for support and assistance. For example, primary care givers may depend on the formal resource for emotional support advice and for material assistance. They may depend on the formal resource systems for recreational, material assistance and other social services.

### **3.8 SUMMARY**

In this chapter the following topics have been discussed, i.e., changing family structure and care giving patterns, stigma and discrimination, perceptions of illness in traditional Africa, AIDS and poverty, characteristics and attitudes of primary care givers and support networks. The crucial issues in each case have been raised and discussed in this chapter.



## **CHAPTER FOUR**

### **RESEARCH METHODOLOGY**

#### **4.1 INTRODUCTION**

In this chapter, the researcher discusses the major components of the methodology. This includes the research design, the sampling procedure, the tools of data collection, the research instrument and analysis.

#### **4.2 RESEARCH DESIGN**

The researcher used the descriptive design because the study was aimed at investigating the attitudes of primary care givers in caring for HIV/AIDS orphans. According to Bobbie (1992:89) "a research design attires the planning of scientific inquiry designing a strategy for finding out something."

For this study the researcher used the qualitative as well as the quantitative type of research because the researcher believed that the qualitative method could describe reality in verbal terms. Qualitative research was also chosen because it looks into complexes, attitudes of primary care givers towards caring for HIV/AIDS orphans. The quantitative method could also help the researcher to use figures to present data easily.

According to Neuman (1997:30) "the quantitative data method refers to the collection of data using numbers, counts and measures of things and qualitative research basically involves the use of words, pictures, description and narratives. The principal objective research design is to reveal potential relationships

between variables" (McKendrick 1993:257). Descriptive studies attempt to describe the phenomenon in details (Bailey 1987:38).

#### **4.2.1 The sampling procedure**

In the selection for a sampling technique, the researcher ensures that each element had an equal chance of being included in the study (McKendrick 1993:269).

##### **4.2.1.1 The population**

"Selection of the population or sample provides the answer to the questions of who will be the respondents in my study?" (McKendrick 1993:268). In this research the population consisted of the primary care givers who care for HIV/AIDS orphans at Ingwavuma, KwaZulu-Natal. The researcher interviewed the primary care givers who are caring for HIV/AIDS orphans.

##### **4.2.1.2 The sampling strategy**

The researcher used the probability sampling procedure for the study. McKendrick (1993:269), states that "a probability sample is one in which all elements of the population have a known chance of selection, no element is assured of selection and no element is excluded from selection a complete list of the population, that is, a sampling frame is required."

Neuman (1997:39) also states that in probability sampling each element in the population has a chance of being included in the sample and the investigation can determine the chances of each element being included in the research.

In this study the researcher used the stratified and judgmental procedures because she knew the primary care givers who are caring for HIV/AIDS orphans and women who participate in Ingwavuma Orphan Care Project.

Sheaffer *et al.* (ibid.) further state that stratified sampling is a method for obtaining a greater degree of representativeness by decreasing the probable sampling error, rather than selecting a sample from the total population at large. The researcher ensures that the appropriate number of elements is drawn from homogenous subjects of that population.

In choosing the respondents in the study, the researcher used the systematic random sampling where ten (10) respondents were chosen from social security files in Ingwavuma Welfare office and ten (10) respondents were chosen from files of primary care givers who are in the database of Ingwavuma Orphan Care Project.

#### **4.3 RESEARCH INSTRUMENT**

The type of research instrument used in this study for collection of data, comprised of an interview schedule.

According to Treece (1986:301) an interview schedule is defined as a questionnaire that is read to the respondent, whereas the interview guide is one

that provides ideas but allows the interviewer freedom to pursue relevant topics in depth.

The interview schedule was constructed in English and then translated into isiZulu and administered in the same isiZulu language as almost the majority of the respondents have a low educational level. The research instrument covered the following areas.

An interview schedule was used which enables the researcher to probe both verbal and non-verbal cues of the respondents and this gave the interviewer the opportunity to clarify matters where necessary.

The researcher used the structured interview with structured questionnaires. According to Treece (1986:300) "interviews are not permitted to change the specific wording of the interview question schedule. They must try to conduct each interview in precisely the same manner and they cannot adapt questions for a specific situation or pursue statements to add to the data."

In this study the researcher used the interview schedule, which, consisted of both open and close-ended questions. "A close-ended question is one in which the respondents answers are limited to the choices offered to them" (Treece 1986:280).

"An open-ended question allows the subject to complete the questionnaire item with an appropriate response in his or her own words" (Treece 1986:279).

The researcher consulted the project documents; previous study on care of HIV/AIDS orphans, project reports for NGO's and other articles related to HIV/AIDS orphans. Different government departments and NGO's caring for HIV/AIDS orphans were key informants for the study.

#### **4.4 DATA ANALYSIS**

"Analysis of data answers the question of how." How small I arrange and order my findings? The data was qualitatively analysed in terms of categories (discreet descriptions) and/or transformed into statistically accessible forms by quantitative counting procedures (McKendrick 1993:275).

Analysis was partly seen as an ongoing process that was a major concern from the beginning of the research project. The information gathered during data collection was analysed in the form of statistics, tables, graphs and coding of collected data. Qualitative data generated by semi-structured interview and face-to-face interviews were analysed through a process of coding and categorizing.

The collected data were coded, presented into graphs and categorized in the manner that the reader can easily understand.

#### **4.5 RELIABILITY AND VALIDITY**

According to Babbie (1983:131) the concept of 'reliability' refers to a particular technique, applied repeatedly to the same object that would yield the same result each time.

"Interview tests, reports from sources familiar to the subject and direct observation may all be used in the question approach to accurate information in research" (McKendrick 1993:275). The researcher's main concern was whether the study would measure the variable and hypothesis intended and whether the measuring device measured the concept as is theoretically defined.

To ensure the validity and reliability of the findings, the researcher used the Social Workers working in Ingwavuma District and Orphan Care workers employed at Ingwavuma Orphan Care Project. Social workers and Orphan Care workers were chosen because they are actively involved in caring for HIV/AIDS Orphans. Social Workers and Orphan Care workers also formed the key informants for the study.

The researcher used the interview schedule supplemented by observations where the researcher observed the attitudes, emotions, behaviour and beliefs towards HIV/AIDS Orphans. Articles, reports and other documents were also used to limit personal biases for the study.

#### **4.6 SUMMARY**

In this chapter, the researcher has explained and attempted to discuss the methods employed in the collection of data. The study was a descriptive design and the data analysed comprised of quantitative and qualitatively semi-structured questions. Both of these were used for the collection of data.

The following chapter outlines the findings of the study.

## **CHAPTER FIVE**

### **PRESENTATION, ANALYSIS AND INTERPRETATION OF DATA**

#### **5.1. INTRODUCTION**

In this research findings are presented, analysed and discussed. The findings are presented according to the interview schedule used in collecting data of the study. The researcher has presented data using graphs, tables and descriptions of findings.

The main aim of the study was to find out the attitude of primary care givers towards the caring for HIV/AIDS orphans in Ingwavuma district. A sample of twenty respondents was drawn from the population of primary care givers. The interview is attached as Appendix A.

#### **5.2 SECTION A: IDENTIFYING PARTICULARS ✓**

5.2.1 The rationale for asking this question was to determine the age of the respondents in case it has any relationship with the attitudes of the primary care givers.

**Table 5.1            Age distribution**

| Age          | No. of Respondents | Percentage |
|--------------|--------------------|------------|
| 07 – 20      | 0                  |            |
| 20 – 40      | 4                  | 20         |
| 40 – 50      | 4                  | 20         |
| 50 – 60      | 9                  | 45         |
| 60 and above | 3                  | 15         |
| <b>Total</b> | <b>20</b>          | <b>100</b> |

Table 5.1 revealed that the majority of the respondents total to 45% of ages ranging from 50 – 60 years of age. They are primary care givers.

#### 5.2.2 Marital status ✓

The question was asked to confirm the marital status of the primary care givers.

**Table 5.2    Marital Status**

| Status        | No. of Respondents | Percentage |
|---------------|--------------------|------------|
| Married       | 3                  | 15         |
| Divorced      | 1                  | 5          |
| Widowed       | 10                 | 50         |
| Never married | 6                  | 30         |
| Living single | 0                  | 0          |
| <b>Total</b>  | <b>20</b>          | <b>100</b> |



Table 5.2 indicates that (50%) of the respondents are widows who care for HIV/AIDS orphans. The researcher is of the opinion that the mortality rate of HIV/AIDS is high, therefore, there is quite a number of widows who care for HIV/AIDS orphans. This is based on the high mortality rate.

5.2.3 Educational level

The researcher asked this question to find out the educational levels of the primary care givers.

Figure 5.1 Educational level

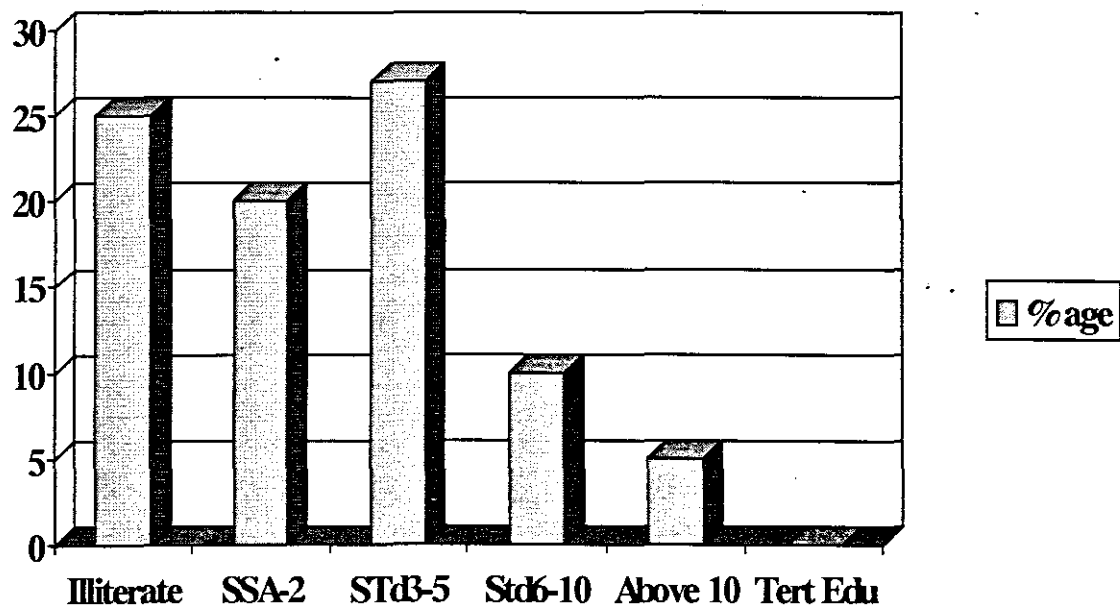


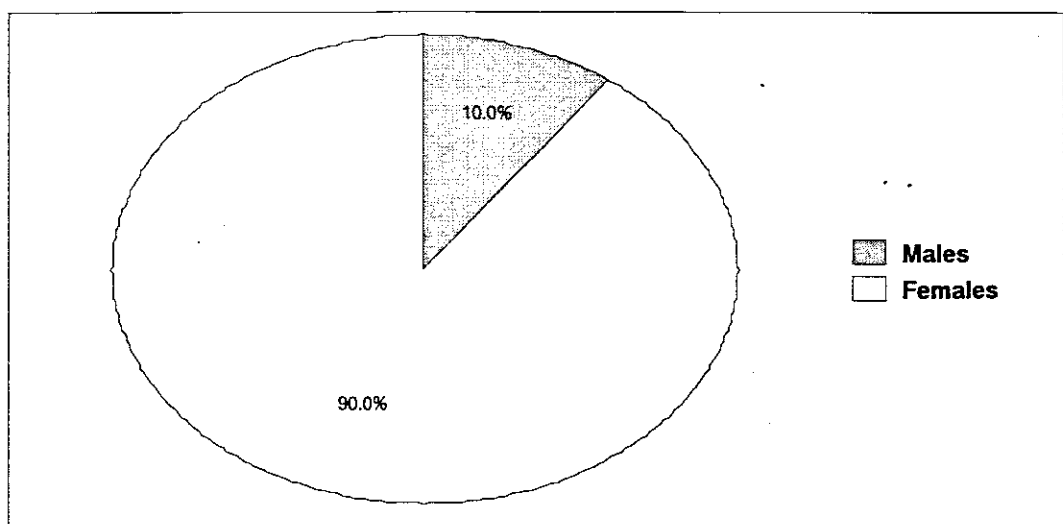
Figure 5.1 indicates that most of the primary care givers have attained primary school education. The findings revealed that 25% of the respondents were illiterate.

This ties very well with Costin (1972:345) who states that foster parents are generally recruited from lower socio-economic groups. They are persons with minimal education, are older than the foster children's own parents and often live in rural or suburban areas quite distant from the social and health resources of Metropolitan communities.

#### 5.2.4 Gender ✓

The rationale for asking this question was to determine the gender difference of primary care givers.

**Figure 5.2 Gender**



The findings revealed that the majority of the respondents 18, (90%) are women. These findings are also supported by Van Dyk (2001:112) who stresses that at the family level the burden of care is predominantly borne by women and girls.

#### **5.2.6 Number of children under the care of the Primary Care Givers ✓**

The researcher asked this question to determine the number of vulnerable children who are cared for by primary care givers per household.

The findings revealed that the majority of the respondents (90%) are caring for a total number of children ranging from 03 to 06 years.

#### **5.2.7 Age distribution of HIV/AIDS orphans ✓**

The rationale for asking this question was to find out the age distribution of HIV/AIDS orphans who are cared for by primary care givers

The findings revealed that the majority of the respondents, 70% care for HIV/AIDS orphans ranging from 05 – 10 years. This is supported by a joint report, Children on the Brink (July 2002). "HIV/AIDS is having a devastating impact on the world's most youngest and most vulnerable citizens. One of the most telling and troubling consequences of the epidemic is the growing number of children it has orphaned and seriously impacted on society. Today more than 13 million children are currently under the age of 15. These have lost one or both parents due to AIDS."

### **5.2.8 Attitudes and problems of primary care givers, in caring for HIV/AIDS orphans ✕**

The rationale for asking this question was to determine whether the age of the child under the custody of the primary care giver does have an impact on the attitude of both the primary care giver and the child.

The findings revealed that those primary care givers who care for children under the age of 10, do not experience any problems but those who care for children, ages ranging from 10 – 20 years, experience behaviour problems, for example, lack of respect, rejecting attitude and adjustment problems.

## **5.3 SECTION B: CHANGING FAMILY STRUCTURE AND CARE GIVING PATTERNS**

### **5.3.1 Health status ✓**

The researcher asked this question to determine whether the status of the primary care giver does influence the attitude of the primary care giver towards caring for HIV/AIDS orphans.

Through data analysis it came out clearly that most respondents were not willing to reveal their status.

5.3.2 The findings revealed that the majority of the respondents (90%) were not willing to know about their HIV/AIDS status. Only (10%) were willing to know. ✓

This ties up well with De Beer and Swanepoel (2000:204) when they state that "AIDS influences human dignity because infection with this disease goes hand in hand with stigmatisation and discrimination. These symptoms of this disease are frightening, knowledge about it is limited and the mode of transmission is associated with socially unacceptable behaviour. Misconception about its spread adds to the stigma."

5.3.3 The question was asked to determine whether the children are receiving any support from the extended family. ✓

The majority of the respondents, (90%), reported that they are not getting any support from the extended family. These findings ties up well with the White Paper for Social Welfare 1997, 89 which states that "while many families appear to be willing to care for the AIDS sick and to nurture and socialise orphans, some are not able to do so owing to the financial strain, poor living conditions or the absence of close relatives to provide the necessary care and support."

## **5.4 SECTION C: STIGMA AND DISCRIMINATION**

### **5.4.1 Problems experienced by primary care givers in caring for HIV/AIDS orphans.**

The rationale for asking this question was to determine the problems that are being experienced by the primary care givers in caring for HIV/AIDS orphans. All respondents (100%) mentioned basic needs like:

- Food
- Clothing
- School fees
- School uniform
- Money to access health services.

This is confirmed in the Constitution of South Africa, Rights of Children which clearly states that every child has a right to life and so their basic physical needs must be met, such as food, shelter and clean water (Community Help for Children living in an HIV Positive World 2002:13).

### **5.4.2 Attitudes of other children towards the HIV/AIDS orphan**

The researcher asked this question to determine whether the other children accept the HIV orphans. The findings revealed that all respondents, 20 (100%) did not experience any problems with the placement of these children.

### **5.4.3 Selection criteria**

This question was asked to find out whether a proper screening procedure was done to determine the capability of the primary care giver.

All the respondents reported that circumstances such as being a close relative or the last word said by the deceased before he or she died, or the relative has been staying with the children before the death of their parents, forced them to become primary care givers of these children.

### **5.4.4 Attitude experienced**

The question was asked to find out the attitudes of the community and neighbours towards the HIV/AIDS orphans.

The findings revealed that the community and neighbours appreciate what the primary care givers are doing, i.e., caring for HIV/AIDS orphans, but that they do not want to be physically involved. They in fact distance themselves immediately after the death of the parents.

This is supported by a Joint Report (Children on the Brink 2002:2), which says that the countries hardest hit by HIV/AIDS care for orphans and children affected by HIV/AIDS lies primarily with their families and communities. But AIDS is placing a huge burden on the extended family

sub-system "the backbone of African societies," while also ravaging entire communities. This leaves many orphans with little support.

## **5.5 SECTION D: AIDS AND POVERTY**

### **5.5.1 Source of income**

This question was asked to determine the source of income for each and every household, which, care for HIV/AIDS orphans.

The findings revealed that the majority of the respondents (60%), live on subsistence farming, 20% on government grants and 20% on money generated from arts and craft sales.

HIV/AIDS leads to financial vulnerability of individuals and families. They often lose their formal sector employment, which can affect the entire household if the person is the key breadwinner with dependants in rural areas. HIV/AIDS creates additional costs, which may place households, which are indirectly affected by the death or illness of a person with HIV/AIDS. For example, families who receive orphans or who are involved with care giving patterns of some sort, feel this strain.



5.5.2 Income for households

The researcher asked this question to determine the amount of income per household.

Figure 5.3      Income per Household

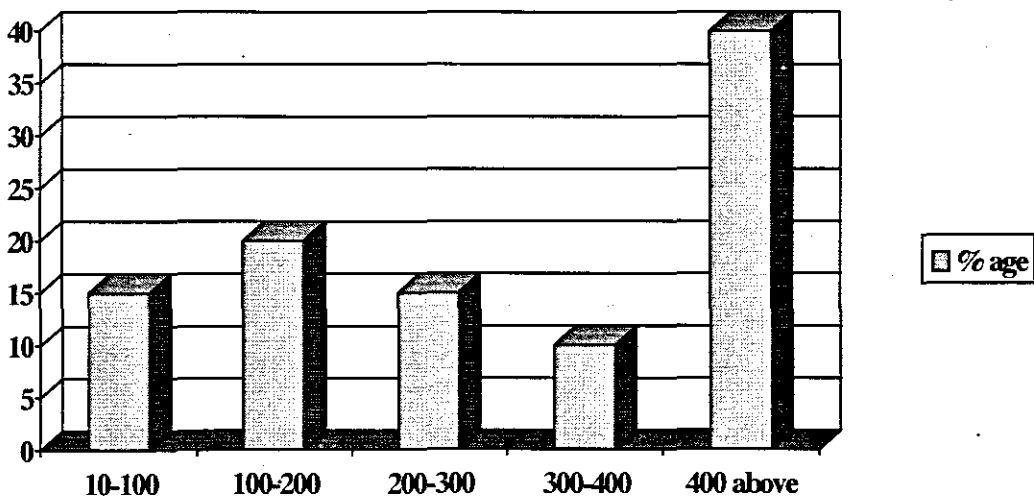


Figure 5.3 revealed that, (40%) of the respondents' income per household ranges from R400-00 and above. The researcher is of the opinion that, most of the primary care givers from rural areas are dependent on government grants for survival. This is why the income ranges from R400-00 and above.

### **5.5.3 The relationship between AIDS and Poverty**

The question was asked to determine whether there is any relationship between AIDS and poverty.

The findings revealed that there is a strong relationship between AIDS and poverty. During the data analysis the respondents mentioned that they incurred:

- Various expenses like caring for a bedridden patient who is terminally ill, i.e., there is thus a need for soap to wash his clothes now and again.
- Transporting the patient to access health services to both the traditional healers and to medical practitioners
- The death of a breadwinner causes more financial strain on the family.

These findings are supported by De Beer and Swanepoel (2000:201) when they say HIV/AIDS has an impact on the family. In the family more time and money are spent on caring for persons suffering from AIDS. This leaves less time to earn money, resulting in fewer resources to care for the household with the added burden of money to be spent on medical care for the infected person. To pay for this care, people may be forced to sell their land or livestock, withdraw from their savings or borrow from others,

which will burden the already weak household. When the infected person eventually dies, funeral costs are added to this burden.

5.5.4 The rationale for asking this question was to find out whether the income per household met all the needs of the family.

5.5.4.1 The findings revealed that the money received by each and every household which, was caring for orphans, did not meet all the needs of the family.

5.5.4.2 The findings revealed that the respondents think that the situation could be improved by making the government social security grants more available to everybody in the community.

## **5.6 SECTION E: POLICY ON ORPHAN CARE**

### **5.6.1 Training**

This question was asked to determine whether the primary care givers did receive any training before the placement of these children with them.

The findings revealed that all respondents, (100%) did not receive any training.

### **5.6.2 Counseling of primary care givers**

The rationale for asking this question was to find out whether the primary care givers did receive counseling or not.

The findings further revealed that all respondents, (100%), did not receive any counseling. The researcher is of the opinion that counseling is important.

Van Dyk (2000:201) supports this where he states that the aim of counseling or helping a client must always be based on the needs of the client. The purpose of counseling is twofold:

- To help clients manage their problems more effectively and develop unused or underused opportunities to cope more fully; and
- To help and empower clients to become more effective self-helpers in the future.

### **5.6.3 Counseling of HIV/AIDS orphans**

The researcher asked this question to find out whether orphans did receive any counseling before and after placement with the primary care giver or not.

- The findings revealed that the respondents were concerned about the delay in the processing of grants .
- The respondents were also concerned about the foster care grant which does not meet the needs of the children, and
- They were also concerned about the lack of training especially on parenting and coping skills.

## **5.7 SUMMARY**

Although the primary care givers care for these children there is no training or counseling that they have been exposed to. These children especially those in their teens have behavioral problems, which need to be attended to. Both the children and the primary care giver need to be trained on trauma counseling and coping skills.

This chapter has presented, analysed and interpreted the data that was gathered.

## **CHAPTER SIX**

### **CONCLUSIONS AND RECOMMENDATIONS**

#### **6.1 INTRODUCTION**

In this chapter, the researcher restates the findings of the study, draws conclusion and make recommendations. The objectives of the hypothesis of the study are also restated.

#### **6.2 RESTATEMENT OF THE OBJECTIVES OF THE STUDY**

The objectives of the study were as follows:

- To determine the attitudes and problems of primary care givers in caring for HIV/AIDS orphans;
- To investigate whether the present government policies are meeting the needs of primary care givers in caring for HIV/AIDS orphans;
- To address the identified problems through resources provided by the Government, if any.

## **6.3 FINDINGS OF THE STUDY**

The following were the findings of the study based on the information obtained from the respondents:

### **6.3.1 Identifying Particulars**

- The findings revealed that the majority of the respondents, that is, 45% of them were of ages ranging from 50 – 60. It is noted that HIV/AIDS infects young adults, generally and the burden of care is usually borne by elderly women.

### **6.3.2 Marital status**

- The findings further revealed that, 50% of the respondents who care for HIV/AIDS orphans are widows. This shows that the mortality rate of HIV/AIDS is high; hence, the number of families, which are headed by women, is gradually increasing.
- The findings again revealed that, 25% of the respondents were illiterate and 20% had attained primary school education. This shows that the primary care givers are from a lower socio-economic background and they have minimal education.
- These findings tie up well with Costin (1972:345) who states that, "Foster parents are generally recruited from lower socio-

economic groups. They are persons with minimal education. They are also older than the foster children's own parents and often live in rural or suburban areas quite distant from the social and health resources of metropolitan communities."

- The findings showed that 90% that is the majority of the respondents who care for HIV/AIDS orphans are women. This clearly shows that in most circumstances the people who are directly involved in the care and nurturing are women.

These findings tie up well with (Van Dyk 2001:112) who stresses that at the family level the burden of care is predominantly borne by women and girls.

### **6.3.3 Educational Level**

- The findings revealed that 25% of the respondents were illiterate and 20% attained primary school education. This shows that the primary care givers are from a lower socio-economic background and they have minimal education.
- These findings tie up well with Costin (1972:345) who stated that "Foster parents are generally recruited from lower socio-economic groups. They are persons with minimal education. They are also older than the foster children's own parents and often live in rural or sub-urban areas quite distant from the social and health resources of metropolitan communities.



#### **6.3.4 Gender**

- These findings showed that 90% is the majority of the respondents who care for HIV/AIDS orphans are women. This clearly shows that in most circumstances the people who are directly involved in the care and nurturing are women.
- These findings tie up well with (Van Dyk 2001:112) who stresses that at the family level the burden of care is predominantly borne by women and girls.

#### **6.3.5 Age of the orphans in relation to the attitudes and problems experienced by primary care givers in caring for HIV/AIDS orphans**

- The findings revealed that 90% of the respondents are caring for orphans with ages ranging from 03-06 years.
- The findings also showed that 70% of the respondents care for orphans ranging from ages 05-10 years. This shows that before they died, the parents of these children were still at a young age or in their middle ages.

Costin (1972:339) states that controlling children other than one's own are apt to produce special problems especially if their behaviour is demanding aggressive or otherwise troublesome. Primary care givers may find

themselves plagued by doubts about their usual methods of discipline and uncertain about action to take in behaviour control.

It was noted that those primary care givers who care for children under the age of 10, did not experience any problems. These include the lack of respect, a rejecting attitude and adjustment problems in new environment.

#### **6.3.6 Attitudes and Problems Experienced by Primary Care Givers in Caring for HIV/AIDS orphans \***

- The findings revealed that the respondents were forced by circumstances to take care of these children. They were either related to the children or they accepted this responsibility because they normally respect the last words that were said by the parents of these children before the death of the deceased.

This is supported by a Joint Report, Children on the Brink (2002:9), which states that the death of both parents of a young family is a major catastrophe for children. It is now left on the extended family to decide as to which family member will assume responsibility over the children.

### **6.3.7 Stigma and Discrimination**

- The findings revealed that 90% of the respondents were not willing to reveal their HIV/AIDS status only 10% were willing to know. This shows that as they are caring for these HIV/AIDS orphans they, themselves are not willing to go for a test because of the stigma and discrimination attached to the disease.

This ties up well with De Beer and Swanepoel (2000:204) when they state that "Aids influences human dignity because infection with disease goes hand in hand with stigmatization and discrimination. These symptoms of this disease are frightening knowledge about it is limited and the mode of transmission is associated with socially unacceptable behaviour misconceptions about its spreads adds to the stigma."

### **6.3.8 Changing Family structure and care giving patterns**

- The findings revealed that the majority of the respondents, 90% reported that they do not receive support from the extended family.
- The findings also revealed that although the community, friends and neighbours appreciate what primary care givers are doing in caring for HIV/AIDS orphans, they did not want to be physically involved or their support is minimal.

### **6.3.9 The Relationship between Aids and Poverty**

- The findings showed that 60% of the respondents are dependent on subsistence farming for a living. Most of their time is spent on the fields ploughing, and 20% earn a living by making hand craft. Caring for a sick person at home takes most of their time.
- The findings clearly show that there is a strong relationship between aids and poverty. This ties up well with a study into the situation of child headed household (January 2001:24) where it is stated that HIV/AIDS leads to financial vulnerability of individual and families. They often loose their formal sector employment, which could affect the entire household if the person is the key breadwinner with dependents in rural areas.
- HIV/AIDS creates additional costs, which may place households that are indirectly affected by the death or illness of a person with HIV/AIDS feel the strain for example, families who receive orphans or who are involved with care giving patterns of some sort.
- The study further revealed that the money received by each household did not meet the needs of the family.

### **6.3.10 Resources**

- From the study, it was shown that the majority, 70% were aware of resources existing in the area.
- It was observed that all respondents saw a need for the existence of these resources.

### **6.3.11 Placement Procedure**

- The study revealed that all respondents did not undergo any screening before the placement of these children
- The findings also revealed that all the respondents did not receive any counseling.
- The study eventually revealed that HIV/AIDS orphans did not receive any counseling. The researcher is of the opinion that counseling is very important in the lives of these children.
- Barnard (2002:10) supports this where she states that counseling before and after the death of the children's parents makes orphaned children to lead a better school performance and a more positive attitude towards life.
- The findings further revealed that the placement procedure, which is followed by the Department of Welfare, still needs to

be improved. The respondents were also concerned about the delay in the processing of foster care grants.

- The respondents recommended that the government need to assist the community or sufferers in accessing social security services. They were also concerned about the future of these vulnerable children.

#### **6.4. RECOMMENDATIONS ✓**

##### **6.4.1 Stigma and Discrimination**

- Education is a process. Change cannot happen overnight. Communities need to be educated about HIV/AIDS so that their attitude towards this disease can change.
- Orphans must not be targeted in isolation from other vulnerable children. As in the case with all vulnerable children and their families, they should be exposed to normal challenges, activities and opportunities which promote participation and development.

##### **6.4.2 Attitudes and Problems experienced by primary care givers ✓**

- In addressing the needs of the primary care givers it is recommended that they be trained in parenting, trauma counseling and coping skills and income generating skills.

- Support groups need to be initiated by all stakeholders in each Tribal Court:
- Workshops with HIV/AIDS orphans need to be conducted where all their problems, needs and expectations could be identified and programs for addressing these problems can be initiated.
- Programmes that promote attitudes of acceptance and supported towards people living with HIV/AIDS should be encouraged.
- Primary care givers should be encouraged to form support groups within their communities.

#### **6.4.3 Orphan Care ✓**

- It is recommended that more social workers be employed for the purpose of attending to the needs and problems of vulnerable children and their care givers.
- Social workers need to be given further training and support so that they can deal more efficiently with the impact of HIV/AIDS in their working environment.
- The criteria for exempting children from paying school fees need to be reviewed standardized and simplified.

- Services should be accessible effective and efficient and it should be inter-sectoral and be delivered by a multi-disiplinary team

#### **6.4.4 Resources**

- The family is the first socializing institution in society. It is recommended that policies that promote the preservation of this basic unit of society be strengthened.
- Communities, as a resource must be encouraged to provide support systems for both children and their care givers.
- Programmes focusing on vulnerable children must be linked to development programmes as taking in consideration the child's needs and that of her care givers.
- It is recommended that the Government should provide subsidies for all organization which are rendering services towards with HIV/AIDS.

#### **6.4.5 Strategies**

- In assisting the primary care givers to cope with the social consequences of HIV/AIDS. It is recommended that home based community care services and family orientated strategies be promoted. The community need to be encouraged and be motivated



to practise what is called "ubuntu".

- Social-work practioners need to be trained on HIV/AIDS related care and support. This training should be introduced at both undergraduate and post graduate levels.
- The government need to develop a joint national and provincial strategy which is going to promote intersectoral collaboration.
- Child Care Forums need to be initiated in each Drop-in-Centre. This forum to address the stigma and discrimination experienced by children who are infected and affected by HIV/AIDS.
- To promote awareness of HIV/AIDS pandemic in all level i.e. National, Provincial and District level.

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## THE INTERVIEW SCHEDULE

### TOPIC

THE ATTITUDE OF PRIMARY CARE GIVERS TOWARDS CARING FOR HIV/  
AIDS ORPHANS IN THE INGWAVUMA DISTRICT.

### SECTION A

Instructions: In the spaces provided tick one box that is applicable to you.

#### 1. Identifying particulars

##### 1.1 How old are you?

|              |  |
|--------------|--|
| 07 – 20      |  |
| 20 – 50      |  |
| 50 – 60      |  |
| 60 and above |  |

##### 1.2 Marital status

|                 |  |
|-----------------|--|
| Married         |  |
| Divorced        |  |
| Widowed         |  |
| Never married   |  |
| Living together |  |

##### 1.3 Educational level

|                    |  |
|--------------------|--|
| Illiterate         |  |
| SSA – Std 2        |  |
| Std 3 - Std 5      |  |
| Std 6 – Std 10     |  |
| Above Std 10       |  |
| Tertiary education |  |

##### 1.4 Gender

|        |  |
|--------|--|
| Male   |  |
| Female |  |

##### 1.5 Number of children under your care

|              |  |
|--------------|--|
| Less than 03 |  |
| 03 - 06      |  |
| 06 – 09      |  |

|              |  |
|--------------|--|
| 09 – 12      |  |
| 12 and above |  |

1.6 How old is the orphan you are caring for?

|              |  |
|--------------|--|
| 00 – 05      |  |
| 05 – 10      |  |
| 10 – 15      |  |
| 15 – 20      |  |
| 21 and above |  |

1.7 Do you experience any problems in caring for the child / children under your care who are under the age group you have just mentioned?

.....

.....

.....

.....

## SECTION B

2. Changing family structure and care giving patterns

2.1 Do you know whether you are HIV positive or not

|                       |  |
|-----------------------|--|
| I don't know          |  |
| I know                |  |
| I do not want to know |  |

2.2 Do you want to know?

|     |  |
|-----|--|
| Yes |  |
| No  |  |

Please explain briefly.

.....

.....

.....

.....

2.3 Do you think children receive adequate support from the extended family?  
Please explain.

.....

.....

.....

.....

## SECTION C

### 3. Stigma and discrimination

3.1 List and discuss three problems you may experience in caring for orphans

.....  
.....  
.....

3.2 Do your own children accept these children? Tick: Yes or No? Please comment on your answer.

.....  
.....  
.....

3.3 How were you selected to be a primary care giver? Explain briefly.

.....  
.....  
.....

3.4 What attitudes do you experience within the community, neighbours and friends?

## SECTION D

### 4. AIDS and Poverty

4.1 What is your source of income?

|                   |  |
|-------------------|--|
| Farming           |  |
| Government grants |  |
| Employed          |  |
| Handcraft         |  |
| Other             |  |

4.2 The income per household ranges from

|               |  |
|---------------|--|
| Less than 100 |  |
| 100 – 200     |  |
| 200 – 300     |  |
| 300 – 400     |  |
| 400 and above |  |

4.3 Do you think AIDS causes poverty?

|              |  |
|--------------|--|
| Yes          |  |
| No           |  |
| I don't know |  |

If yes, describe:

.....

.....

.....

4.4 Is the income adequate to meet all the needs of the family?

|              |  |
|--------------|--|
| Yes          |  |
| No           |  |
| I don't know |  |

If no, what do you think could be done to improve the situation?

.....

.....

.....

.....

## SECTION E

### 5. Policy on Orphan Care

5.1 Did you receive any training before you took over the custody of these children? Yes / No. If yes, what type of training?

.....

5.2 Did you receive counselling before and after the placement of these children? Yes / No. If yes, what did the counselling entail?

.....

.....

5.3 Did the children receive counselling before they were placed under your care? Yes / No? If yes, explain how.

.....

.....

.....

5.4 List any non-Governmental organization involved in caring for orphans that you are aware of.

.....

.....

.....



5.5 Do you think the services they render are of value and necessary?

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5.6 What are your suggestions about the procedure, which is followed by the Department of Welfare in the placement of children? State briefly.

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---

**THANK YOU**

# UHLA LWEMIBUZO

**LOLUCWANINGO LUBHEKA IZINKINGA NENDLELA ABABHEKI  
BEZINTANDANE ABABHEKA NGAZO NABAKHULISA NGAYO IZINTANDANE  
ZEGCIWANE LENGCULAZI**

## ISIGABA SOKUQALA

1. Imibuzo emayelana nawe

1.1 Uneminyaka emingaki?

|                 |  |
|-----------------|--|
| 07 – 20         |  |
| 20 – 40         |  |
| 40 – 50         |  |
| 50 – 60         |  |
| 60 nangaphezulu |  |

1.2 Isimo sokushada

|                |  |
|----------------|--|
| Ushadile       |  |
| Wehlukanisile  |  |
| Ungumfelokazi  |  |
| Awukaze ushade |  |
| Nihlalisene    |  |

1.3 Izinga lemfundo

|                      |  |
|----------------------|--|
| Awufundile           |  |
| SSA – Std 2          |  |
| Std 3 – Std 5        |  |
| Std 6 – Std 10       |  |
| Ngaphezu kuka Std 10 |  |
| Okunye               |  |

#### 1.4 Ubulili

|             |  |
|-------------|--|
| Owesilisa   |  |
| Owesifazane |  |

#### 1.5 Zingaki izingane ozinakekelayo

|                   |  |
|-------------------|--|
| Ngaphansi kwezi 3 |  |
| 03 – 09           |  |
| 06 – 09           |  |
| 09 – 12           |  |
| 12 nangaphezulu   |  |

#### 1.6 Zineminyaka emingaki?

|                 |  |
|-----------------|--|
| 00 – 05         |  |
| 05 – 10         |  |
| 10 – 15         |  |
| 15 – 20         |  |
| 21 nangaphezulu |  |

#### 1.7 Zinkinga zini ohlangabezana nazo ekukhuliseni abantwana abakule minyaka abanayo njengoba ubakhulisa?

.....

.....

.....

.....

.....

### ISIGABA SESIBILI

#### 2. Ushintsho esimweni somndeni

##### 2.1 Uyazi yini ukuthi unalo igciwane noma cha?

|                |  |
|----------------|--|
| Uyazi          |  |
| Awazi          |  |
| Awufuni ukwazi |  |

## 2.2 Uyathanda ukwazi?

|      |  |
|------|--|
| Yebo |  |
| Cha  |  |

Chaza ngempendulo oyikhethile.

.....

.....

.....

.....

.....

## ISIGABA SESITHATHU

### 3. Ukucwasa nobandlululo

3.1 Yiziphi izinkinga ohlangabezana nazo ekunakekeleni izintandane zengculazi. Beka zibe ntathu.

.....

.....

.....

.....

3.2 Abantwana bakho bayabemukela yini lababantwana abayizintandane? Yebo noma Cha. Uma uthi CHA, yini eyenza bangabamukeli? Chaza.

.....

.....

.....

.....

3.3 Wakhethwa kanjani ukuba ngumbheki walababantwana? Chaza kafishane.

.....

.....

.....

.....

3.4 Bakuthatha kanjani omakhelwane abangani nomphakathi wonkana njengoba ungumbheki walezi zintandane? Chaza.

## ISIGABA SESINE

4. Ubumpofu nengculazi

4.1 Uphila ngani, kanjani?

|                      |  |
|----------------------|--|
| Ngokulima            |  |
| Ngempesheni          |  |
| Uyasebenza           |  |
| Ngomsebenzi wezandla |  |
| Ngokunye             |  |

4.2 Inani lemali engenayo lisuka ngaphansi kuka

|                  |  |
|------------------|--|
| Ngaphansi kuka   |  |
| 100 – 200        |  |
| 200 – 300        |  |
| 300 – 400        |  |
| 400 nangaphezulu |  |

4.3 Ucabanga kanjani ngabe ingculazi iyaholela ebumpofini?

|        |  |
|--------|--|
| Yebo   |  |
| Cha    |  |
| Angazi |  |

- 4.4 Imali engenayo ekhaya iyakwazi yini ukuhlangabezana nezidingo zonke zempilo yomndeni?

|        |  |
|--------|--|
| Yebo   |  |
| No     |  |
| Angazi |  |

- 4.5 Uma uthi cha, singenzenjani ukulungisa isimo sibe ngcono? Chaza.

.....

.....

.....

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## ISIGABA SESIHLANU

5. Umthetho kaHulumeni omayelana nokunakekelwa kwezintandane zeNgculazi

- 5.1 Waluthola yini uqeqesho ngaphambi kokuthi uthole ilungelo lokunakekela izintandane? Uma uthi yebo, hlobo luni loqeqesho?

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- 5.2 Waluthola yini usizo lokunakekelwa ngokomphefumulo ngaphambi nangemuva kokuba lezi zintandane zibekwe ngaphansi kwesndla sakho? Uma uthi Yebo, chaza ukuthi kanjani.

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- 5.3 Izintandane zona zaluthola yini usizo ngokomphefumulo ngaphambi kokuba zibekwe kuwe? Yebo noma Cha? Uma uthi Yebo, chaza.

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5.4 Ngokwakho sikhona isidingo salezizinhlelo?

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5.5 Beka imibono yakho maqondana nendlela uMnyango wezeNhlalakahle onika ngawo amagunya kubabheki bezintandane ukuba babheke lezi zingane.

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**SIYABONGA KAKHULU**

## DC27

