

A SITUATIONAL ANALYSIS OF
CHILDREN LIVING WITH
TERMINALLY ILL PARENTS

By Dr Ann Barnard

Dissertation submitted in partial fulfilment
of the requirements for the degree of Master
of Philosophy in Maternal and Child Health

University of Cape Town

2003

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

I, Ann Elizabeth Barnard declare that this thesis embodies only my original work except where acknowledgement indicates otherwise and that no part of it has been or is being submitted for a degree at any other university.

The work for this thesis was done in the School of Child and Adolescent Health of the University of Cape Town.

University of Cape Town

Abstract

Background

While there is a lot of literature available on the negative effects of orphanhood on children, little attention has been paid to children in the period before their parents die when they are living with a sick parent. This study seeks to focus on such children to gain greater understanding of their situation.

Aim

To describe the problems and coping strategies of children living with and caring for their terminally ill parents.

Design

This study is a cross-sectional descriptive survey.

Setting

A rural district in a middle-income country.

Main outcome measures

Demography of households, symptoms of the sick parent, attributes of child carers, how children deal with specified symptoms of their parent's illness, greatest perceived hardships faced, type and quantity of help from outside sources and extended family.

Results

Thirty five households were interviewed using a structured questionnaire. Households were found to be poor with difficulty accessing services. Most parents had symptoms consistent with AIDS and over 30% died within two months of the interview. Pain ranked as the most troublesome symptom.

One hundred children aged four to eighteen were involved to some extent in the care of their sick parents. Male children were the main carers in 40% of households. The children generally dealt appropriately with the parents' symptoms and correctly identified what pills they were taking and what the pills were for.

Seventy one percent of carers believed that their parent would get better. The children identified their greatest hardships as hunger (43%), lack of money for school (29%) and parent's illness (19%). Sixty nine percent asked for material support and the same number requested financial support for schooling.

Support from relatives was mostly provided by grandmothers and aunts. Five provided food, five cared for the sick person and three helped with child care. Ten of the 35 households were never visited by relatives staying outside the homestead.

From the wider community, neighbours were the most supportive group practically, helping with food and nursing. Church groups were active in praying with families but most did not help materially or practically. Eight families received support from local non governmental organisations and only two were visited by the Department of Welfare.

Conclusions

Poverty was the overriding issue negatively impacting on the families. It prevented adequate access to health care, nutrition and schooling. Poor infrastructure and government services further compounded these problems as well as preventing access to water, sanitation, education and government grants.

Children were often found to be caring for their parents with little external support and would benefit from training as well as supervision and counselling from trained health workers. The children's role as carers frequently interfered with school attendance yet many of their teachers were unaware of their home circumstances and did little to support them. Teachers' awareness of the social problems facing learners needs to be raised.

Support by the extended family and community is often superficial and generally targets the sick parent while ignoring the children. Greater attention needs to be paid to the psychological and material needs of the children in these vulnerable families.

TABLE OF CONTENTS

ABSTRACT	III
LIST OF FIGURES	IV
LIST OF TABLES.....	V
ACKNOWLEDGEMENTS.....	III-V
GLOSSARY.....	VII-IX
INTRODUCTION.....	1
1.1 BACKGROUND TO RESEARCH	1
1.2 DESCRIPTION OF THE PROBLEM	2
1.3 SIGNIFICANCE OF SPECIFIED PROBLEM.....	4
1.4 PURPOSE OF INVESTIGATION.....	4
OBJECTIVES.....	4
LITERATURE REVIEW	6
2.1 EFFECTS OF THE AIDS EPIDEMIC ON THE HOUSEHOLD IN AFRICA	6
2.1.1 Alterations in household make-up.....	6
2.1.2 Economic consequences	8
2.1.3 The needs of the terminally ill adult.....	8
2.2 THE IMPACT OF THE AIDS EPIDEMIC ON CHILDREN.....	10
2.2.1 The psychological impact of sickness and bereavement on children.....	10
2.2.2 Impact on Children's Health.....	12
2.2.3 Impact on nutrition and food security.....	13
2.2.4 Social Problems of orphanhood and parental illness.....	13
2.2.5 Impact on Education.....	15
2.3 THE ROLE OF CHILDREN AS CARE PROVIDERS	17
2.4 TRADITIONAL AFRICAN PRACTICES FOR CARING FOR THE SICK AND CHILDREN	18
2.5 THE IMPACT OF HIV/AIDS, INCREASING POVERTY AND SOCIAL CHANGE ON TRADITIONAL CARING PRACTICES	19
2.6 HOME BASED CARE	20
2.6.1 Models of home based care	20
2.6.2 Effectiveness of home based care	21
2.7 THE SOUTH AFRICAN GOVERNMENT'S PLANS	22
2.8 SUMMARY	23
METHODOLOGY.....	25
3.1 LITERATURE REVIEW.....	25
3.2 QUESTIONNAIRE DESIGN	25
3.3 ETHICAL APPROVAL	26
3.4 COMMUNITY PARTICIPATION	26
3.5 SAMPLE SELECTION.....	26

3.6 FINDING THE HOMESTRADS	28
3.7 THE INTERVIEW	28
3.8 DATA ANALYSIS	30
3.9 FUNDING FOR THE RESEARCH.....	30
RESULTS.....	31
4.1 DEMOGRAPHIC PROFILE.....	31
4.2 FAMILY STRUCTURE.....	34
4.3 PROFILE OF THE SICK PARENTS.....	37
4.4 CHILD CARERS.....	38
4.5 COMMUNITY SUPPORT FOR THE FAMILIES.....	44
4.6 DISCRIMINATION AGAINST THE CHILDREN IN THE HOUSEHOLDS	47
DISCUSSION.....	48
5.1 DEMOGRAPHY OF HOUSEHOLDS	48
5.2 FAMILY STRUCTURE	50
5.2.1 <i>Description of the family constitution</i>	50
5.2.2 <i>Economic potential of the households</i>	51
5.2.3 <i>Sickness and death in the households</i>	52
5.3 PROFILE OF THE SICK PARENTS.....	53
5.4 EXPERIENCES OF THE CHILD CARERS	54
5.4.1 <i>Description of the children</i>	54
5.4.2 <i>Impact on schooling and socialising</i>	55
5.4.3 <i>Children as bread-winners</i>	56
5.4.4 <i>Children's ability to care for their parents</i>	57
5.4.5 <i>The children's worries and perceived needs</i>	59
5.4.6 <i>Support requested by the children</i>	61
5.4.7 <i>Perception of their future</i>	62
5.5 COMMUNITY SUPPORT FOR THE HOUSEHOLDS	62
5.6 PROBLEMS CAUSED BY THE COMMUNITY FOR THE FAMILIES.....	66
5.7 LIMITATIONS OF THE STUDY	66
CONCLUSIONS	69
SOCIOECONOMIC CONDITIONS	69
THE DYING PARENTS	69
CHILDREN'S ABILITY TO CARE FOR THEIR PARENTS	69
EFFECT ON SCHOOLING	69
SUPPORT FROM EXTENDED FAMILY	70
SUPPORT FROM THE WIDER COMMUNITY	70
ACCESS TO SERVICES	70
RECOMMENDATIONS	72
7.1 POVERTY ALLEVIATION AND COMMUNITY DEVELOPMENT.....	72
7.2 COORDINATION AND STRENGTHENING OF SERVICES	72
7.3 SUPPORT OF FAMILIES AND CHILDREN	74

7.4 FURTHER RESEARCH.....	75
REVIEW OF KEY ISSUES.....	77
REFERENCES.....	79
APPENDIX.....	85

University of Cape Town

LIST OF FIGURES

<i>Number</i>	<i>Page</i>
Figure 1. Orphaned and unorphaned children in school in selected countries. Source UNICEF,DHS (1994-9).....	16
Figure 2: Type of dwelling of study households	30
Figure 3: Type of toilet of study households.....	32
Figure 4: Distance walked to fetch water	33
Figure 5: Distance from households to schools.....	33
Figure 6: Adults in the households	34
Figure 7: Ages of children in the households	35
Figure 8: Ages of sick family members.....	36
Figure 9: Deaths in the last 3 years	36
Figure 10: Age of main care giver	39
Figure 11: Children's expectation of the parent getting better.....	42
Figure 12: Support by different sectors of the community.....	44
Figure 13: Frequency of visits from the extended family.....	47

LIST OF TABLES

Table 1: Symptoms of illness experienced by the sick parents..... 38

University of Cape Town

ACKNOWLEDGMENTS

The author wishes to thank the brave parents and children who agreed to take part in this study and share something of their lives with the outside world. My hope is that by doing so the world will become more aware of their plight and the plight of the thousands like them facing the full effects of the AIDS epidemic with very little support.

I would also like to thank my field workers who helped to track down the families, often spending hours driving around on wild goose chases or walking up and down mountains and even barefoot across rivers in the sweltering heat or rain. It was an education for us all.

I would finally like to thank my tutor, J. Henley, for her valuable advice and motivation to keep going to the bitter end.



GLOSSARY

AIDS Acquired immunodeficiency syndrome. A collection of signs and infections indicating the terminal stages of infection with the human immunodeficiency virus.

CBO Community based organisation; typically a grass-roots organisation formed by civic society.

CINDI Network The children in distress network. A consortium of organisations and individuals that network in the interests of children affected by HIV/AIDS in and around the Durban and Pietermaritzburg areas of KwaZulu Natal.

DOTS Directly observed therapy short course– the method used for ensuring that patients comply with their six month's treatment for tuberculosis.

FOST Farm orphan support trust of Zimbabwe

Friends of Mosvold Hospital A trust fund established by the hospital to help channel funds to projects which can help benefit the health of the population of Ingwavuma health district.

GP A medically qualified general practitioner.

HBC Home based care

HIV The human immunodeficiency virus responsible for causing AIDS (see above).

Kraal The traditional homestead where the extended family stays surrounded by a thorn fence

NGO Non-government organisation.

Nompilo. Community health worker. There are 160 of these in Ingwavuma Health District.

Pap Maize meal- the staple food in Ingwavuma

STD Sexually transmitted disease; a disease typically, but not always exclusively transmitted through sexual intercourse e.g. AIDS, syphilis, gonorrhoea, chlamydia, herpes.

Shemula water scheme A scheme which purifies water from the Pongola River and pipes it to parts of the health district. Water can be bought at water towers at a rate of 1 cent per litre.

Traditional healer A person trained to heal people either through divination or through using local herbs.

UNAIDS Joint United Nations programme on HIV/AIDS

VIP. Ventilation improved pit latrine; a pit toilet with a pipe to allow better air flow and reduced smell and flies compared to a simple pit latrine.

WHO World Health Organisation

University of Cape Town

Chapter 1

INTRODUCTION

1.1 Background to research

Ingwavuma District is a deep rural district lying in 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 covers some 2100 km² and has an estimated population size of 110 000. The terrain consists of the Lebombo Mountains in the west, and the Pongola flood plains in the east. Homesteads are scattered over the whole health district without any formalised grouping in the way of villages. There is a higher concentration of homesteads around Ingwavuma Town, and the Ndumu area which both boast a small shopping centre, post office and an Ithala Bank, but the majority of people live in remote homesteads several hundred metres from the nearest track or road.

People survive through migrant labour, subsistence farming and the sharing of government grants. Thirty six percent of households have no regular source of income (Demographics 2002). The extended family structure is still strong, and polygamy is practised in some parts of the district. Many women have five or more children, and it is not uncommon to find mothers with ten children. There are no local statistics for HIV available, but the KwaZulu Natal antenatal figure of 36% seems to reflect the number of AIDS deaths.

Mosvold Hospital is a 246 bedded district hospital, which is situated in the town of Ingwavuma. The hospital has had an AIDS Team since 1990 and has long been aware of the impending epidemic in the health ward. Now, as the epidemic reaches a mature phase, the AIDS Team has shifted its role from prevention and counselling to

include care for the dying and the orphans left behind. In 2000, the team put together a comprehensive plan to tackle the epidemic at all levels. This included providing support to orphans in the community, and in June 2000, Ingwavuma Orphan Care was established. Ingwavuma Orphan Care is a non-profit organisation, which was started as a joint venture between the Departments of Health, Welfare and Agriculture. It receives private funding and employs a full time coordinator who is responsible for meeting the aims of the project. The project helps orphans who are living in the community through advocacy to access government grants, payment of school fees, community mobilisation, provision of food and clothes parcels and raising awareness of the orphans' problems. As well as identifying orphans who have lost both parents, the project registers children who are living with sick and terminally ill parents. There were 1200 children registered with the project in October 2001, and it is suspected that there are hundreds more in the district that have not yet been identified. Children are being registered at a rate of 100 per month.

In October 2001, Mosvold Hospital AIDS Team also received funds to start up a Home Based Care project. It is modelled on the "Integrated community-based home care" (ICHC) model (DeFillipi 2000), started by South Coast Hospice, which has proved successful in rural areas. Home Based Carers were trained from November to January, and started work in February 2002, towards the end of the data collection period. The project provides support to people dying at home as well as their families, and dovetails with the work of the orphan project. Initial funding has allowed for the project to commence in five communities in the health ward. It is hoped that further funding will eventually allow expansion to cover the whole health district.

1.2 Description of the Problem

The number of orphans in KwaZulu Natal is growing at an alarming rate. It is estimated that there are already between 197 000 and 250 000 orphans in the province and that by 2015 orphans will comprise 9-12% of the total population (Desmond & Gow 2001). While other countries in sub-Saharan Africa have already

felt the full impact of the AIDS epidemic and have developed models to cope with the terminally ill and the orphans, the government is still looking for ways to provide meaningful care in the South African setting. Currently in South Africa there are more people infected with HIV than in any other African country. Without significant changes in treatment or sexual behaviour it is predicted that about 15% of children under 15 year and 30% of children 15 to 17 years will be orphaned by 2015 (Bradshaw, Johnson, Schneider, Bourne & Dorrington 2002). However the problems of orphanhood start before the death of a parent. When the sole parent becomes sick the household is often without income and the child must watch the parent slowly die. The country is facing a challenge for which there is little knowledge or experience to draw on. It is vital that research projects surrounding the issues facing affected children are carried out urgently to give health and welfare personnel detailed information about the problems that they must address. This will ensure best use of limited resources.

This research project aims to build on the framework already established by the Ingwavuma Orphan Care Project, to identify the needs of orphans and “pre-orphans”, and to seek ways of strengthening the care of these children in the community. It focuses on “child-headed households”, specifically those in which children are now caring for their dying parents.

The national, provincial and local government are seeking solutions to the orphan problem, as are NGOs such as Nelson Mandela’s Children’s Fund. A rapid appraisal carried out by Smart in 1999 recommended a need for further research into how families and communities can be strengthened to cope with AIDS orphans and vulnerable children. E Wekesa (2000b) of the Kenyan Ministry of Planning and Finance echoed this need for a survey into coping mechanisms at community level and the kind of support required by children affected by HIV/AIDS. A report by Desmond and Gow (2001) comments that “at time of writing no household studies specifically on the impact of HIV had been completed in South Africa, although a number were underway.”

1.3 Significance of Specified Problem

Testing of women attending the antenatal clinic in Mosvold Hospital shows that 50% are now HIV positive (unpublished data). Those children who survive longer than their mother will have to live through their parents' sickness and death before going on to become orphans. This clearly amounts to a significant part of the child population.

While some families still live as extended families, and the children do not face the death of their parents alone, other families exist as nuclear families, and the burden for nursing for the dying parent falls primarily on their children. The death of parents has an impact on children whether or not there are other adults living in the household, and this is a situation that will be faced by at least a third of children in KwaZulu Natal over the next 10 years as the AIDS epidemic matures. Yet this subject has received very little attention throughout the world. This research project aims to highlight issues that need to be tackled, and bring the attention of policy makers, the media and other role players to the needs of these children.

1.4 Purpose of Investigation

The purpose of this research is to describe the problems, external support and coping strategies of children living with and/or caring for their terminally ill parents in the Ingwavuma Health District.

Objectives

- To determine the availability of external support to children caring for a terminally ill parent.
- To describe the affected children's perceptions of their situation
- To explore how child carers manage various symptoms of their parent's illness
- To provide information, which will direct the response of the Departments of Health, Social Development, Education and NGOs to

the growing number of child-headed households caring for terminally ill parents.

University of Cape Town

Chapter 2

LITERATURE REVIEW

Neither words nor statistics can adequately capture the human tragedy of children grieving for dying or dead parents, stigmatised by society through association with HIV/AIDS, plunged into economic crisis and insecurity by the death of their parents and struggling without services or support systems in impoverished communities (UNICEF 1999).

2.1 Effects of the AIDS epidemic on the household in Africa

2.1.1 Alterations in household make-up

It is predicted that the AIDS epidemic will cause an increase in deaths, reduced fertility and thus fewer births, slowing or potentially reversing population growth in Sub-Saharan Africa. By 2010, this part of Africa may have 71 million less people and a greater number of widows, widowers and orphans who will increase dependency ratios (Drimie 2002).

In the past, it was unusual to find homes in Africa headed by single parents, as if one partner died, the other would soon remarry. Women in many African cultures would marry the brother or close male relative of her husband (widow inheritance), thus ensuring that the family line would be cared for and continue. This practise is decreasing, and widows are increasingly left to care for themselves and their children (Ntozi & Nakayiwa 1999). In 1995, it was noted that there was an increase in female-headed households in Uganda (Ntozi & Zirimenya 1999). Ntozi & Zirimenya noted that the majority of widows under 30 years leave their husband's family home after the death of the husband, many under duress of the husband's relatives. These changes have also been noted in Tanzania, where a study also mentions that female-headed households have lower income, less access to food and smaller land-holdings than male-headed households (Hunter, Kajjage, Maarck, Kiondo & Masanja 1997).

A study carried out in the Free State by Boovsen, van Rensburg, Bachmann, Englebrecth & Steyn (2002) noted that HIV infected homes had a smaller supply of labour within the household and a greater number of children and elderly persons than households not affected by HIV. This was also found in Ingwavuma (Schroeder 2003) where households that had taken in orphans were larger and more likely to be female headed than those without orphans. Thus the burden of disease is falling on households least able to cope with it.

Foster, Makufa, Drew & Kralovec (1997) have looked at the emergence of child-headed households. A household is so defined when a child (0-18 years) is the person primarily responsible for the day to day running of the household, child-care, breadwinning and household supervision. An "accompanied child-headed household" is one in which an adult is present, but has no or little responsibility for the household as that person is too old, too sick or disabled. Child-headed households were first noted in the late 1980s in Uganda, and are likely to become increasingly common as the AIDS epidemic worsens. In Foster, Makufa, Drew & Kralovec's study of 43 households, children assumed headship during the mother's terminal illness in 4 households. In most households a child or adolescent assumed headship upon the death of the last remaining parent. Children stayed in their home rather than move in with relatives either because they wanted to (22%), there was no relative (30%), or the relatives did not want the children to move in with them (62%).

There are differing views on the effect of AIDS on the extended family. Hunter, Kaijage, Maarck, Kiondo & Masanja (1997) write; "although it has become popular to say that AIDS is destroying the extended family system in Sub-Saharan Africa, it may simply be hastening its evolution." Foster, Makufa, Drew & Kralovec (1997) comment that the houses headed by children(0-18yrs) or adolescents (13-24 yrs) are a new expression of the extended family's coping mechanism, rather than the result of children slipping through the safety net. In the case of child-and adolescent-headed households, it was found that relatives lived nearby and visited frequently.

2.1.2 Economic consequences

As well as affecting the makeup of the household, AIDS has an adverse effect on the economy of the household. The AIDS epidemic is likely to lead to greater poverty among affected families pushing some non-poor households into poverty and some very poor households into destitution (Drimie 2002).

A study in Uganda (Ntozi 1997a) showed that 75% of AIDS affected households suffered financial problems, in 18% regular work was suspended, and 6.7% experienced social isolation. The Free State Study (Booyesen, van Rensburg, Bachmann, Englebrecth & Steyn 2002) found that households used up an average of 21 months of savings when caring for a sick person and 38 months of savings when a death occurred in the family. A large prospective survey carried out in Rwanda (Donovan, Bailey, Mpyisi & Weber 2003) found that the level of debt increased in 46% of households with a chronically ill adult while another 20% of such households had used their savings during the illness. This study also found that 61% of families had less to eat or a less varied diet when a young male adult was ill, and 44% had less when a female young adult was ill.

“Wol Zaphela izingane” was a study, which was carried out in the Pietermaritzburg region (Marcus 1999). It was an exploratory qualitative investigation of poor peoples’ perceptions of death and dying in the AIDS epidemic. The study highlights the plight of orphans left behind. Invariably there is a drop in socio-economic status on the death of the parents. Those left to care for the orphans find that they did not have enough money to feed and clothe the children in their care, and feel helpless and neglectful. There were only a few instances where the families seemed to be coping. Schroeder (2003) likewise found that orphan households in Ingwavuma were food insecure when compared to families who had not adopted AIDS orphans and were able to grow less than half of their food requirements.

2.1.3 The needs of the terminally ill adult

The course of HIV/AIDS is variable among individuals and typically consists of times of acute illness interspersed with relative wellbeing. There are a wide range of

possible complications and length of survival. Typical common symptoms include pain (52%), tiredness (50%), anxiety (40%) and sleep disturbance (37%) (UNAIDS 2000). Kikule (2003) found that patients' greatest need is for pain relief. In order to improve quality of life, it is important therefore that the HIV positive person has access to health facilities which will provide adequate pain relief and counselling as well as treatment of acute infections.

As well as health needs, ill parents require practical support. In a Ugandan study (Gilborn, Nyonyintono, Kambumbuli & Jagwe-Wadda 2001), HIV positive parents reported that they needed help with child care (80.2%) and help with other daily activities such as fetching water, cooking, shopping (81.3%). They received help some of the time from older children, mothers, siblings and brothers-in-law. However, fear of stigma and rejection has been noted to prevent people living with AIDS from accessing support and treatment (Russel & Schneider 2000).

There need for a "continuum of care" has been well documented (Russel & Schneider 2000). This includes a comprehensive range of services including counselling and testing, clinical management, nursing care and community based social support. Social support covers emotional, psychological, physical, medical and economic support. Most of these are expected to be provided by the family and friends of the sick person (Ntozi 1997a).

Hunger has also been reported to be an issue facing HIV positive people. In a focus group in South Africa, a nurse commented "You know, I really wonder whether some patients aren't dying of starvation and not AIDS" (Russel & Schneider 2000). The problems faced in accessing government grants were also mentioned by the group. This contributes to the inability to access food.

Many ill parents are worried about their children's future, especially concerning their access to food and education (Gilborn, Nyonyintono, Kambumbuli & Jagwe-Wadda 2001, Russel & Schneider 2000). They also worry about their own declining health, deteriorating living conditions and being stigmatised for being HIV positive. Most

realise that there is a need to appoint a guardian for their children, but many do not do so in practise, either because they do not know of someone suitable, or they are afraid to disclose their sickness.

2.2 The impact of the AIDS epidemic on children

As parents and other family members become ill, children take on greater responsibility for income generation, food production and care of family members. They face decreased access to adequate nutrition, basic health care, housing and clothing (UNAIDS 2002).

2.2.1 The psychological impact of sickness and bereavement on children

The strain on children living with their dying parents has been described in Uganda (Senegendo & Nambi 1997). Sixteen percent of the 15-19 year olds in the study combined schooling with caring for their sick parent, while 9% left school to care for the sick parent. At the start of the parents' illness, 18% were sad but hopeful, 39% felt sad and hopeless, 30% were too young to know what was going on. When the parent became very sick, 49% of the children were afraid that the parent would die, while 28% were too young to know. When the parent died, 50% felt very sad and helpless and only 2% felt positive about facing the future. These findings go against the commonly held belief in some African cultures that children do not have emotional problems.

Looking at the psychological effects of bereavement, several stressors are present at the same time; grief over the death of a parent, fear about the future, separation from siblings, distress about worsening economic conditions and HIV/AIDS related stigmatisation and discrimination (UNAIDS 2000). Children have the same fears and concerns regarding HIV as adults and need access to the same information to alleviate these fears (Alidri, Acidri, Mawejje & Ireland 2002). AIDS orphans experience feelings of loneliness, fear, depression and sadness. They need psychological support, but the grieving process is often hindered by the cultural norms and taboos of society, in which children are not expected to have or express feelings (Nanteza, Sharpe, Ssentongo & Nabposa 2000). There is little meaningful communication between adults and children about death and dying. Many children

are separated from their dying parent and excluded from the mourning process. These cultural taboos contribute to the trauma they experience (Beatson 2002).

Children themselves have been able to vocalise these issues in focus groups (Beatson 2002, Alidri, Acidri, Mawejje & Ireland 2002) or using participatory tools such as role play, drawing and ranking (Prang 2000). Problems the children identified include:

- Loss of childhood due to overwhelming household responsibilities
- Lack of communication with care-givers and no one to talk to about their situation
- Inadequate information on how HIV will affect them and their parents
- Poor access to health services
- Limited efforts to reduce stigma and discrimination towards themselves and their families
- Many children are caring for dying relatives without preparation or support

The children in these studies recommend:

- Encouraging adult family members and care givers to involve children in counselling sessions.
- Integrating play into child-targeted counselling sessions.
- Educating children about HIV/AIDS before they are told of a relative's HIV status
- Integrating psychosocial support for children into existing community and home care practises (Alidri, Acidri, Mawejje & Ireland 2002).

These psychological needs are being increasingly recognised and many NGOs have set up programmes to address them. A project in Kampala, Uganda has taken on the issue of working with parents to inform their children about their illness. The mothers write memory books with the children, recording important family history and disclose their status to their children. It has been found that the children involved take an interest in caring for their sick parents and ask questions regarding their own health and that of their parents. They also plan for their future when their parent has died (Nyamayaro 2000).

In Bulawayo, weekly Kids Clubs have been set up to provide psychosocial support to 4500 children. Using 150 youth volunteers, these clubs have led to a better quality of life for the children as well as being a highly effective youth HIV/AIDS prevention strategy (Kaseke & Germann 2002).

2.2.2 Impact on Children's Health

HIV mainly infects young adults many of whom are parents. While only one in three children born to infected mothers will themselves be HIV positive and die in childhood, the health of the HIV negative children is also adversely affected by their parent's sickness and death. In Kenya it is projected that deaths in the under fives will increase by over 15% in the period 1999-2008, while deaths among infants will increase by 8-11% in the same period due to the AIDS epidemic (Wekesa 2000b). The South African Department of Social Development reports that "uninfected children born to infected mothers have a 2.4 to 3.6 times increased mortality rate than children born to uninfected mothers" (Dept Social Development Guidelines). This is thought to be a consequence of children being born with HIV infection, but also due to an increased exposure to opportunistic infections such as tuberculosis and pneumonia, increased poverty and social factors such as lack of proper care of children whose parents die of AIDS (Piwoz & Prebal 2000, Wekesa 2000a).

A rapid appraisal of children living with HIV/AIDS was carried out in 1999 in South Africa (Smart 1999). This states that AIDS produces young orphans, and younger orphans are particularly at risk of death as they tend to be nutritionally deprived, and

less likely to be immunised and taken to health care facilities. In many communities, children whose parents have died from AIDS are at more risk of dying from preventable diseases because any sickness that befalls them is attributed to AIDS and thus regarded as untreatable.

These findings are echoed in a Kenyan paper (Wickesa 2000b) which also emphasised that problems begin long before their parents die. Frequent sicknesses suffered by the parents lead to inadequate care and poor access to food and health care for all family members. The study showed an increase in the under 5 mortality could not be attributed to HIV infection among the children alone.

2.2.3 Impact on nutrition and food security

In South Africa approximately 14 million people are vulnerable to food insecurity. One in four children below the age of six has been stunted due to malnutrition (Schroeder 2003). The Project for Statistics on Living Standards and Development (1994) estimated that 39% of the population were not meeting a daily energy requirement of 2000 kilocalories a day.

Various studies report that being an orphan adversely affects the child's nutritional status. Stunting is higher among orphans than other children, even if other factors are controlled for (Deninger, Garcia & Subbarao 2003). The impact is particularly severe in poor households. AIDS kills the most productive members of the family. Populations dependent on subsistence farming will be particularly affected as families face labour shortages, asset depletion and loss of farming knowledge (Haddad & Gillespie 2001). AIDS increases dependency ratios and impairs the intergenerational transfer of skills, abilities and knowledge within households (Schroeder 2003).

2.2.4 Social Problems of orphanhood and parental illness

Problems in child-headed households are listed as poverty, lack of adult supervision, stunting and hunger, educational failure, lack of medical care, psychological problems, disruption of normal childhood, exploitation, early marriage, discrimination, child labour, property grabbing, homelessness and poor housing (Hunter & Williamson

1997, Smart 1999). A study in South Africa found the AIDS orphans are being ostracised by their communities and exploited by relatives who take them in with the aim of getting a state grant (Thompson 2001). However, studies show that many of these problems start before the HIV infected parent dies, and it is recommended that children living with HIV positive parents need as much help as orphans do (Hunter & Williamson 1997).

The FOCUS Project in Zimbabwe carried out a self-evaluation in 1999 (Lee 2002). This included workshops with the orphans to investigate whether their needs were being met. It was found that the orphans were often discriminated against by their carers, peers and at school. Sexual abuse was also a big problem. The orphans felt that volunteers who came to their households actually spent more time talking to the head of the household, and did not listen to the orphans themselves. Importantly, it was noted that the orphans' perceptions of their needs and the perceptions of the volunteers and project leaders were often quite different. The study concluded that there was a need for greater empowerment of the orphans, and the orphans should have a more active voice in the running of the project themselves.

A Ugandan study which looked at care of orphans showed that 18% of orphans care for themselves, while 45% are cared for by relatives (Ntozi 1997b). The community felt that the orphans received adequate care with regards social support, adequate care in the way of food provision, but poor support with regards provision of education and clothing. Yet another study in Uganda (Ntozi, Ahimbisbwe, Odwee, Aiyga & Okurut 1999) reported that 47% of households assisting orphans lacked money for schooling, compared to 10% of households without orphans. Orphans were more likely than other children to end up stunted and malnourished, and were sometimes robbed of their inheritance or forced into early marriages. Female orphans face more problems than male orphans, being more at risk of sexual abuse and exploitation, while older children are worse affected than younger ones, facing problems of being unable to attend school and more emotional trauma over the parents' deaths (Ntozi 1997b).

2.2.5 Impact on Education

Children also are affected by the impact of the AIDS epidemic on their schooling. The education system is being eroded as teachers and officials at every level die prematurely. These are either not replaced or replaced by less experienced staff. In the Central African Republic, teachers' mortality increased by 13% between 1996 and 1997 (Fassa 2000). Nearer to home, it is reported that Swaziland is losing teachers at an alarming but unknown rate, and there is no clear ministerial strategy to combat the effects of the epidemic (King, Whiteside, Crowne & Thomlinson 2000). In KwaZulu Natal, attrition rates of 6.7% were noted in 1999 and it is estimated that over 60 000 new educators will be required by 2010 just to keep educator/learner ratios at their current level. This is equivalent to the number of educators currently in the state system (Desmond & Gow 2001).

The impact of HIV on the household poverty, as mentioned above, is also reflected in falling school enrolment. Grade 1 enrolment had a historic growth of 3-5% per year over the last 20 years. However since 1999, enrolments have been going down at a rate equivalent to 12% per year. It is thought that this decline in enrolment is largely attributable to HIV/AIDS (Desmond & Gow 2001). The study in the Free State, (Booyesen, van Rensburg, Bachmann, Englebrecht & Steyn 2002) found 5.2% of children in HIV affected houses were not schooling. The percentage was higher for older children in poorer, female-headed households. In Tanzania (Ainsworth, Beegle & Koda 2002), it was found that the death of a parent led to delayed enrolment among young children from low economic status. A Ugandan study (Gilborn, Nyonyintono, Kambumbuli & Jagwe-Wadda 2001) found that day to day school attendance was worse among older children living with HIV positive parents than for orphans of a similar age. This suggested that the children were being taken out of school due to an increase in domestic responsibilities at home. Overall it has been seen that orphans are less likely than non-orphans to be at a proper educational level, with the effect being stronger at younger ages (6-10 years) than older (11-14 years). Loss of both parents has greater impact than loss of one (Bicego, Rutstein & Johnson

2003). Decreased school enrolment for orphans is well documented (Deninger, Garcia & Subbarao 2003) (Figure 1)

Who is in school?

Percentage of orphaned and unorphaned children (aged 10-14) in school

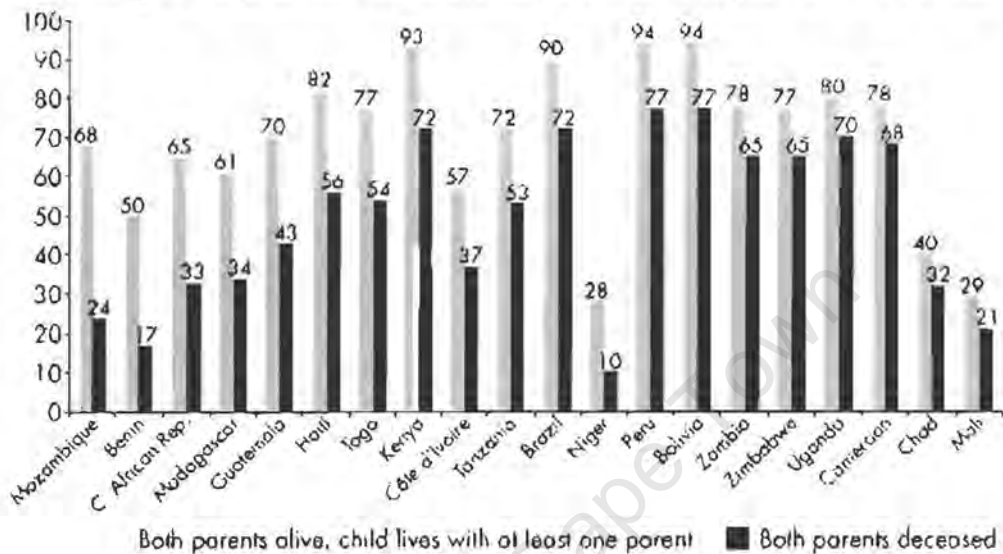


Figure 1. Orphaned and unorphaned children in school in selected countries. Source: UNICEF/DHS (1994-9)

Those affected children who do still manage to attend school may be teased or discriminated against by teachers and peers. At the National Children's Forum in August 2001 (which was attended by orphans from Ingwavuma), children reported being expelled from school, threatened by teachers, excluded from the school feeding scheme or punished for not completing their homework. The teachers were often unaware of the children's home circumstances (Giese 2002a). In Tanzania (Hunter & Williamson 1998), teachers noted negative emotional changes in children who have seen their parents die of AIDS. "Many seemed confused, some acted as if retarded". Twenty seven percent of children in a Ugandan study (Gilborn, Nyonyintono, Kambumbuli & Jagwe-Wadda 2001) reported a decrease in performance at school which they attributed to missing school to care for parents, an increase in household responsibilities, emotional distress and not being able to afford school fees.

2.3 The role of children as care providers

“Those suffering without respite from AIDS are the children of those afflicted, who have watched their parents die, sometimes nursing them alone.” (Hunter & Williamson 1998)

Children are increasingly being forced to take on the role of caregiver and breadwinner. They are unable to access social security grants, being under age, and must rely on neighbours, relatives or organisations for hand-outs. However, few studies to date have focused on this group of care givers.

In Botswana, a study was carried out looking at girls as carers (Tlou 2000). Twenty three rural girls aged 11-16 who were caring for a relative (parent, uncle, aunt, older sibling) were interviewed. The girls did the care giving after school hours. It was found that they had inadequate knowledge about HIV/AIDS, and most were not even aware that their relative had AIDS. They expressed feelings of fear, hopelessness as well as fatigue and lack of sleep from caring at night. They also missed out on time for homework and extracurricular activities.

A study of 200 youth living in slums in Kenya (Kahinga 2000) found that the youth were active in care and support for their peers, parents and family members infected by HIV. However, they lacked basic medical and nursing skills, counselling skills, information on infection control, hygiene and nutrition. They were willing to receive training so that they could be better carers.

A positive model of child carer is found in Kenya (Lenya, Dimba, Aduwa & Odiembo 2002). Here the Association of People with AIDS in Kenya (TAPWAK) has acknowledged the role of children as carers and provides training for them. Children's roles include maintaining hygiene, dispensing medicines (both oral and intravenous), continence care, pain control and family care. The children are counselled and taught about HIV/AIDS prevention, nursing and home based care by community workers. The project leaders comment that the children are useful as alternative care providers. The children in turn benefit by gaining a greater understanding of HIV/AIDS, learning nursing skills and forming a preventive and

supportive partnership in caring for people with AIDS. However, it is not reported how this role impacts on the children's schooling, recreation time and socialisation.

2.4 Traditional African practices for caring for the sick and children

Most African communities had strong kinship ties and extended families which function as social support systems in times of need. In many African societies failure of family members to care for the sick is believed to invoke the deceased person's spirit against the culprits (Ankrah 1993). A traditional care system has been described in southwest Uganda (Ntozi 2000) where the principal carers for the sick are women. The women who care for the sick of both sexes are relatives such as grandmothers, mothers, sisters, sisters-in-law, cousins and aunts. However if a male is seriously unwell, women apart from the wife are excluded from caring for the patient as they are not allowed to handle the private parts of other relatives. In these cases male relatives such as adult sons, brothers and cousins become the carers.

Within the extended family system, children who are orphaned are usually taken in by a relative such as an uncle or an aunt (Gilborn, Nyonyintono, Kambumbuli & Jagwe-Wadda 2001). However, Madhavan (2003) argues that in South Africa traditional family life was already severely disrupted by apartheid, even before the AIDS epidemic, due to male labour migration to the mines. This led to children being fostered by a variety of kin and non-kin. As men left the villages to work on the mines and live in hostels, children were either cared for by their mothers or moved around other relatives if both parents lived in hostels (Ramphele 1993). Such child-rearing during apartheid had negative consequences for the children involved. Finchman and Thomas (1984) found that malnourished children were more likely to come from homes where they were cared for by someone other than their mother. Burman and Fuchs (1986) noted that children of divorced couples ended up in the care of relatives and encountered health problems and delayed educational progress. Fostered children were also discriminated against and made to work harder while given less access to household resources than biological children (Vaan der Waal 1996).

2.5 The impact of HIV/AIDS, increasing poverty and social change on traditional caring practices

In 2001, the United Nations Secretary General noted that the AIDS epidemic was changing the way communities operate and destabilising traditional support systems (Drimie 2002).

In Uganda it was found that the extended family is finding it increasingly difficult to cope with caring for sick members as those who are left are themselves too young, too old or too sick (Ntozi & Nakayiwa 1999). Patients were found to be cared for by parents (45%), siblings (17%), and their children (3.8%) in 1992/3. The number cared for by their children had risen to 4.5% in 1995. Another Ugandan study, carried out in 1997 (Ntozi 1997a), found that primary carers were parents (38%), spouses (18%) and children (11%). Thus the percentage of children being left to care for their parents can be seen to be increasing with time. Clan members were expected to help with nursing, food and arranging funerals, however, in reality additional support was minimal.

A study in Botswana found that care of sick patients was left exclusively to female family members. Some had to quit their jobs in order to care for the sick person (Kelesitse 2000). Caring at home can therefore have severe economic repercussions for the carer. In addition the carer may feel isolated and stigmatised (Magada 2002). In Tanzania (Hunter & Williamson 1998), it was noted that support from family members and friends may be more available in the early phases of the illness, but finances are exhausted by the illness and funeral and there is then little financial help left to support the orphans.

Regarding the care of children, there is debate as to how well the extended family is coping. Ankrah (1993) states that while HIV/AIDS has forced a reorganization of the family and clan structure, there is every reason to be optimistic that the new arrangements can succeed. She states that even child-headed households are often linked to the larger clan. Hunter (1990) agrees with this, stating "In Uganda,

traditional fostering systems have been able to bear the additional burdens created by AIDS and it is our bias that they continue to do so”.

However, the United Nations Children’s Fund (UNICEF 1999) is more pessimistic; reporting that Africa’s safety net for orphans in the shape of deep rooted kinship ties is unable to cope with the growing numbers of orphans as a result of the AIDS epidemic in the most affected countries (Drimie 2002). Nyambedha, Wandibba & Aagaard-Hansen(2003) in Kenya found that there was significant lack of participation of the larger extended family in support of orphans. Most assistance was confined to the household resources in which the orphan was accommodated. This was partly attributable to poverty but it was also thought that changes in traditional values brought about by modernization have changed the role of the traditional family. Clearly the debate is still open and ongoing research is needed to find out what is the true situation.

2.6 Home Based Care

2.6.1 *Models of home based care*

The Partnership for Home Based Care in Rural Areas, Uganda, has noted that care of the sick and dying is carried out on four levels; clinic-based (including doctors and nurses), community-based (including community health workers and volunteers), home-based (including family and friends) and self-based (involving the patient himself) (UNAIDS 2001). There is a need to build bridges between these levels of care. Eight examples of “best practise” in care have been identified by UNAIDS. These models function along the principles laid down in the WHO’s 1993 Home Care Handbook which encourages comprehensive care, a continuum of care, integration with government services, a prevention component and use of local resources. Typically the projects included in the review train local community workers who visit affected families providing support in the way of basic nursing training, provision of basic medicines, advice on drawing up wills, and in some cases provision of food. Few however seem to address the needs of the child carers.

Apart from TAPWAK, detailed above, the only other model identified which targets child carers is the Kariobangi Community Home Based Care Programme, started in 1986, to provide support to families at their homes. They run a Child Crisis Centre where children caring for sick parents can receive training in caring for sick parents and how to bring up younger siblings. They may return to the centre at any time for ongoing advice and support (UNAIDS 2001, Eight case studies).

Models of Home Based Care also exist in South Africa, with the “integrated community-based home care” (ICHC) model, started by South Coast Hospice, being seen as one of the most successful (Defilippi 2000). In this model, volunteers are trained in basic nursing and counselling skills. The volunteers visit sick people in their communities and train the family on how to care for the sick person and provide psychological support. The carers are supported and monitored by qualified nursing staff. The Masoyi Project in Mpumalanga, the Centre for Positive Care and a few others also uses volunteers to provide HBC to the sick. They place emphasis on teaching people to be self reliant rather than dependent on others (Russel & Schneider 2000).

2.6.2 Effectiveness of home based care

Home Based Care (HBC) has been introduced as a cost-effective strategy for caring for the terminally ill in many countries affected by the epidemic. A study of four Home Based Care Projects in Uganda found that the mean survival period of clients on their programmes was 3.5 years. Over 70% of clients never needed admission to hospital. HBC was holistic and three times cheaper than hospital care (Sentumbwe & Nantege 2000).

TASO (The AIDS Support Organisation) in Uganda report that HBC led to clients being more able to disclose their status, a reduction in the number of opportunistic infections and better skills among relatives caring for the clients (Butuuro, Tumusiime, Denyonga & Kaddu 2000). A project in Nairobi, Kenya has noted other benefits including the reduction of stigma and greater AIDS awareness among the

community (Opundo 2000). Thus HBC plays a preventive role in combating the spread of HIV as well as providing care for those infected.

A review of six HBC projects in Malawi (Masika 2000) found that a little input seems to make a big difference to the coping ability and the quality of care given to clients requesting Home Based Care. Greatest needs included food and access to basic health services. The schemes generally provided counselling, practical and material support, basic nursing care, information and advice to relatives. Also in Malawi, Buhendwa, Zachariah & Labana (2002) found that introducing home based care to 995 clients lead to a reduction in morbidity from 50% to 15 %. Stigma disappeared and the people living with AIDS formed groups which provided psychosocial support, solidarity and a positive attitude to life.

However, it should be noted that policies and services provided by home based care programmes are often geared to the needs of the adult and children's needs are often ignored. This was found to be the case in India by Mebra, Sakhuja & Panwar (2002).

2.7 The South African Government's Plans

In South Africa, an HIV/AIDS/STD Strategic Plan (2000-2005) was developed in early 2000. The stated aim of the document was that all Government Departments, organisations and stakeholders would use the document to develop their own plans, so that the initiatives in the country would be harmonised (Dept of Health 2000). In order to deal with the effects of HIV/AIDS on children specifically, the government has drawn up a document entitled "National Integrated Plan for Children Infected and Affected by HIV" (Dept Education, Health & Social Development 2000). This plan is to be implemented jointly by the Departments of Health, Social Development and Education. The four main areas covered by the plan include community based care and support; strengthening voluntary counselling and testing initiatives; life skills and HIV/AIDS education in schools; community outreach/mobilisation. As with the strategic plan, the document has been drawn up at national level, and it is up to provinces to develop their own implementation plans within the guidelines.

A budget has been allocated to this plan, but due to the late transfer of funds, the provinces only spent 36.5% of the budget in 2000 (Desmond & Gow 2001). In short “there is a yawning gap between policy formulation and implementation” (Desmond & Gow 2001). Marcus (1999) also comments that welfare responses are being driven by cost efficiency and economic rationality rather than social obligation and there are few safety nets for poor households and communities.

A food security policy for South Africa (1997) has developed strategies to ensure that there is sufficient affordable food available and that consumers are able to make healthy food choices. The strategies include:

- Agricultural reform in order to optimise the economic empowerment of the more vulnerable and impoverished rural groups.
- Ensuring that those eligible to social security are receiving their government services and in particular targeted benefits.
- Protecting the livelihoods and food security of households during disaster and stress periods.

2.8 Summary

While there is literature available on the effects of AIDS on communities in Africa, very little focuses specifically on the role children are being forced to play as primary care givers for their parents. Furthermore, what literature there is remains unpublished and difficult to find rather than being in high profile journals. This contrasts greatly with the amount of literature available on care of orphans and more medical aspects of AIDS such as the use of antiretrovirals.

Furthermore, there is very little literature being produced by South Africa despite it being a relatively affluent country with the monetary and academic potential to carry out research as well as being the country with the greatest number of HIV positive people in the world (Bradshaw, Johnson, Schneider, Bourne & Dorrington 2002). It

seems clear that there is an urgent need for more research to be carried out into the impact of HIV and chronic illness of parents upon their children. This information is vital to policy makers in formulating plans to reduce the effects of the epidemic upon society.

University of Cape Town

Chapter 3

METHODOLOGY

3.1 Literature review

A review was conducted by search of abstracts from the AIDS 2000 conference, AIDS 2002 conference, internet search using PubMed, contacting organisations involved in care of the terminally ill and orphans around Africa through the CINDI network and internet search of websites such as www.unaids.org, www.mrc.ac.za and www.sarpn.org.za. Further literature was obtained from the "Call to co-ordinated action for children affected by HIV/AIDS" conference, held in Midrand in June 2002.

3.2 Questionnaire design

The study was a descriptive cross-sectional study carried out by using a structured interview based on a questionnaire (Appendix 1). The research project was designed and carried out shortly after ABT Associates, a firm of research consultants, did some research in the district into the economic impact of AIDS on households. It is hoped that the two projects will complement each other in providing managers and policy makers with more information into the effects of AIDS on the population of Ingwavuma.

The questionnaire was designed to be in similar format to the ABT one. Questions included in the questionnaire however were changed to reflect findings and questions raised by the literature review. In line with the ABT survey, the questionnaire was written in English. The questionnaire was divided into six sections; Section 1- Household demographics, Section 2 – Household characteristics, Section 3- Sick parent, Section 4- Child carers, Section 5-Community Support, Section 6-Conclusion.

Three fieldworkers were used; a psychology graduate who was volunteering with the orphan project, a home based carer and an unemployed social development graduate. All were born and lived in the Ingwavuma area and spoke Zulu and English fluently. The fieldworkers were orientated as to the purpose of the study, the inclusion criteria for interviewees and the meaning of the questions. Any clarifications were dealt with prior to going into the field. The home based carer took part in five interviews, the volunteer in twenty and the unemployed graduate in ten. The researcher was present at all interviews. The fieldworkers asked the questions in Zulu and elicited responses. The researcher had a fair grasp of Zulu and translated and recorded the answers on the questionnaire herself. When she did not fully understand the answer given, she sought clarity from the fieldworker.

3.3 Ethical approval

The project was presented to the ethical committee at Mosvold Hospital. The committee wholeheartedly approved the project, believing that it would be of benefit to the families interviewed as well as the wider population.

The research proposal was also presented to the UCT medical ethics board and gained their approval.

3.4 Community participation

As well as informing the members of the local ethical board, the researcher met with community leaders at a Health Advisory Board meeting which was held in October 2001. The purpose of the study was explained to the board as well criteria for inclusion, so that the members present would be aware that the study was being carried out. The board was in agreement with the study and said that it would inform the greater community.

3.5 Sample selection

Criteria for inclusion in the study: Children under 18 years old living with one or both parents who were too sick to carry out daily tasks of living such as fetching water, cooking, gardening and ploughing fields. The household was defined as a group of

people who shared the same living space and usually ate from the same cooking pot. The household could reside anywhere within the Mosvold Hospital health sub-district (Tribal areas of KwaNyawo, KwaMathenjwa and KwaMngomezulu), an area covering 2100km² with an estimated population of 100 000.

The initial intention was to interview families where there were no adult care givers living in the household. However in the pilot phase of the study, this was found to result in a very low yield of households. The criteria for inclusion in the study were broadened to include households where there were other adults living in the household, as long as the children were reported to be involved in the care of their parent.

Families were identified in several ways:

- By extracting names from the records of Ingwavuma Orphan Care. These records contain details of whether a parent has died from suspected AIDS, but do not give a clear picture of whether the remaining parent is still healthy or not.
- By visiting schools, and asking them to identify children who knew of such households. Schools were visited at the start of the study to explain the criteria for households needed for the study, then revisited a few weeks later to collect names and directions to the households.
- By visiting clinics and asking nurses to identify families in their area. Again, this required at least two visits, firstly to ask for help, and then a return visit to get the names and directions.
- By the community health workers and the home based care teams.
- By chance; neighbours or passers-by mentioned families they knew of while the researcher was out trying to track down a referred family.

3.6 Finding the homesteads

There are no telephones, postal addresses let alone streets with names or numbers in the health district. Directions to the homesteads were generally vague. The research team drove to the area named as the address, and then asked for directions from shop-keepers, school children or passer-bys. In some cases, the child of the household was identified as attending a particular school. The school was asked permission to release the child, and the child then directed the team to the household. Otherwise the team had to keep asking people that they met, until they arrived at the household. This process could take several hours. Given these circumstances and the time constraints, it was not possible to visit the families first to inform them of the impending study.

The sample size aimed at was 50-100 households. The researcher was given a time frame of twenty four days spread over twelve weeks to collect data. The sample size of 35 households was reached over these twelve weeks. Altogether 98 households were identified, but the other 63 were found not to meet the study criteria once they had been visited or more information obtained from the neighbours or children. There were undoubtedly a larger number of households eligible for inclusion in this study within the health district. However, it was beyond the time constraints of this study to identify and interview any more. The sample obtained was found by a snowballing technique rather than systematic identification of all households in the district as this would have been beyond the scope of the study.

3.7 The interview

The researcher and field worker visited each household identified by car or by foot. Once a household was reached, the team greeted the household and verified facts about the household set-up. If the household was found to not meet the criteria, the team explained that they were from the hospital and checking on households that had been identified as having a sick patient living there. The family was advised on any relevant issues such as eligibility for disability grants, inclusion in the orphan project or home based care project. The sick person was also given some basic medical

treatment (e.g. paracetamol, vitamins) if needed. The research team then left the household.

The household was defined as people sharing the same food and sleeping in the same huts. In three instances there were other relatives living in other huts within the same kraal, but in most cases the household was the only one within the grounds.

If the household met the criteria for the study, the field worker explained the research project to the household head, and confidentiality was assured. The household head was identified by the family. He/she was a person who was sleeping at the homestead and regarded as being ultimately in charge of decision making. The household head was asked for consent to take part in the research, and if he/she agreed, he/she signed the consent form. The interviewer then interviewed the household head, and filled out Sections 1-3 of the questionnaire. If the household head was too sick to be interviewed, as was the case in one household, details were obtained from the oldest, mentally competent person living at that household.

The child carer was then identified by asking the household head which child spent most time caring for the ill parent. The field worker then asked the child carer for his/her assent to take part in the interview. If the carer was present, he/she was interviewed in the household, but apart from the rest of the family. This was done so that the child could express his/her concerns in privacy. If the carer was at school, the team went to the school with the parent's permission, and interviewed the child there. On a few occasions, the carer could not be found, and the team had to come back for a second visit. The child carer was asked the questions from Section 4-6. In Section 6, the family discussed their general problems with the team.

The heads of households were asked questions without any prompting for the answers. Regarding the questions asked to the child carers, Q4.3 was asked without prompting possible answers while Q4.8, 4.10 & 4.11 were asked with the possible answers given as examples. In Sections 5-6 no prompts were given.

The research team then informed the household of the help they were entitled to and where they could get it. Children were counselled about how they could better care for their parents. Any families not known to the orphan project were referred. The sick parent was given basic medical treatment as needed. The researcher (a medical doctor) carried a basic medical kit with her to each household. Each family was also given a small food parcel, as lack of food was found to be a universal problem. In this way, the visit was not just of benefit to the researchers, but also provided the family with relevant education, health care and material support.

3.8 Data analysis

The data were coded and entered into Microsoft Excel. This programme was used to analyse the data and generate graphs and tables. The qualitative answers were reviewed and transcribed from the interview sheets directly into the results section. No comparisons of subsets were carried out due to the small size of study sample.

3.9 Funding for the research

A grant for the research was given by Health Systems Trust. This grant was used to pay the field worker a daily stipend, to cover travel expenses of the researcher, to buy food parcels for the households interviewed and to cover stationary costs. While the inclusion of a food parcel lead to some families coming forward to be interviewed who were not eligible, the researcher explained the criteria for the study and firmly turned them down. Most families, however, were unaware that they would be given a food parcel at the end of the interview and this is unlikely to have altered their responses to the questionnaire. The researcher does not believe that a food parcel constituted an undue inducement to households to enter the study. Rather, the food parcel was offered to compensate the household for the time they gave to be interviewed. The food parcel was thus a token of appreciation for their willingness to participate in the study and share sensitive information.

Chapter 4

RESULTS

A total of 35 households were included in the study. Between them, they included 78 adults (>18 years) and 137 children (< 18 yrs).

4.1 Demographic Profile

The families included in the study were generally poor, as is typical of the profile of Ingwavuma. Nobody included in the study was in paid employment, although some households may have had access to government grants and pensions. Two of the sick parents were still working, selling dried fish and traditional bees. They said that they worked when they were able, but when they were sick the family went without income or food. The majority of households lived in traditional huts made out of sticks and mud, stone or reeds depending on local availability of building material (Fig 2). It was noted that those living in brick structures were not necessarily well off; the family may have been more affluent in former times, but sickness and death had reduced these families too to poverty.

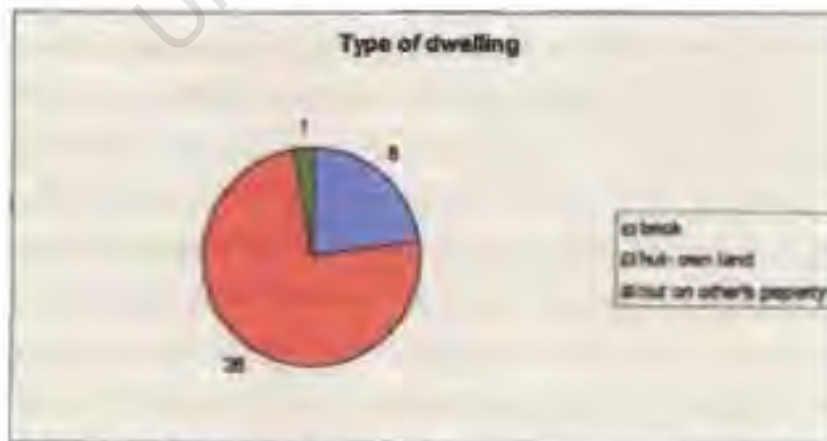


Figure 2 Type of dwelling of study households

Not a single household had access to water at the homestead, but all had to travel some distance to fetch water. Eighteen households (51%) walked less than fifteen minutes to fetch water (Fig 4).

Twenty six households (74%) did not have a toilet but used the surrounding bushes and fields to relieve themselves (Fig 3). Again this is typical of the district (Demographica 2002).

While twenty six households (74%) lived within 30 minutes walk of a primary school, only thirteen (37%) lived within 30 minutes walk of a secondary school. (Fig 5) The children all walked to school.

Only nine households (26%) lived within 30 minutes walk of a clinic or hospital. Thus accessing medical care for the sick parent could be difficult for most families.

Twenty six households (74%) lived near a shop. However, "shop" generally means a very basic tuck-shop which would only stock the most basic commodities, and sometimes on an irregular basis.

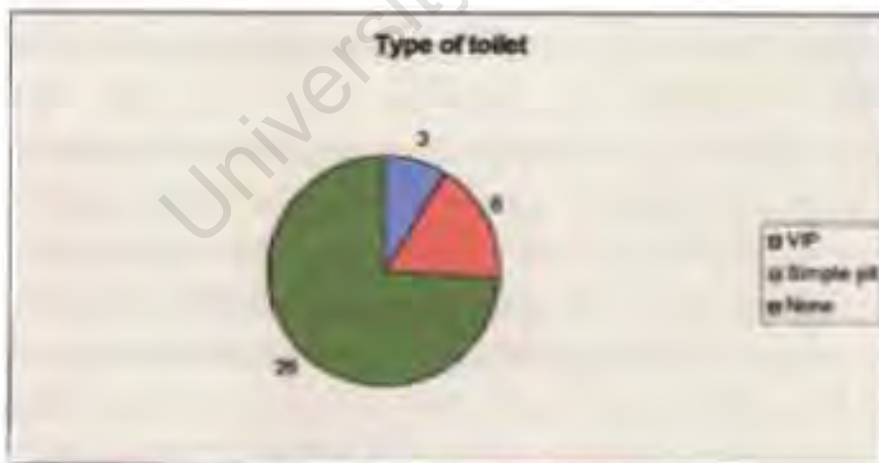


Figure 3: Type of toilet of study households

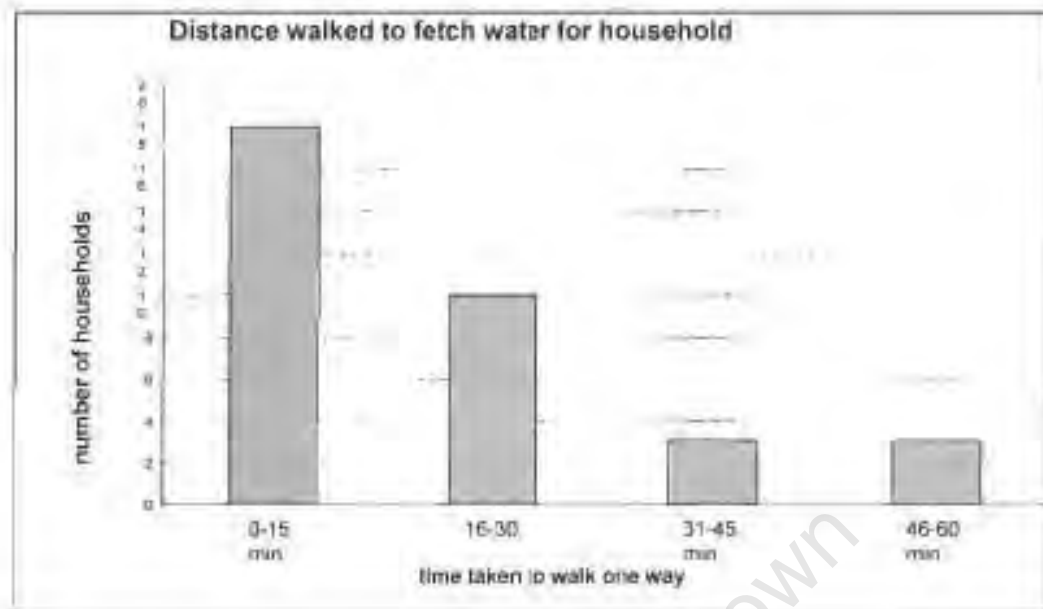


Figure 4: Distance walked to fetch water

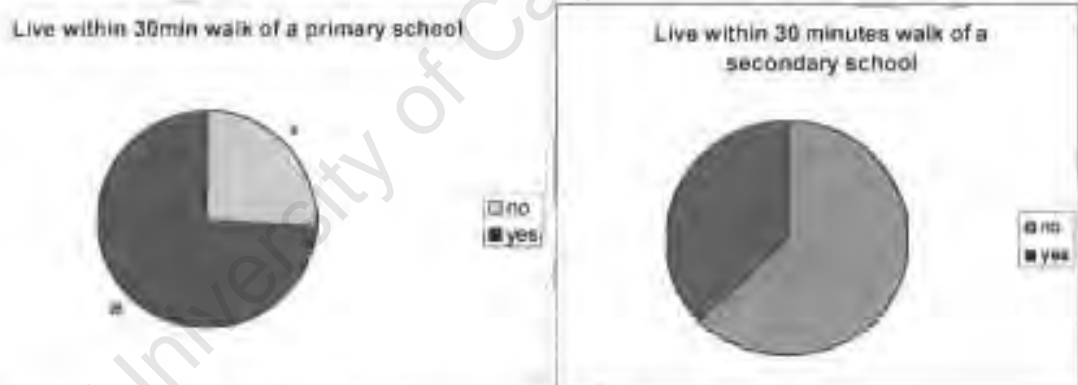


Figure 5: Distance from households to schools

Twenty five households (71%) lived within 30 minutes walk of public transport. It should be noted however that a 30 minute walk for a healthy person may be impossible for a sick person. For some households it was necessary to climb up or down steep slopes and even, in one case, wade across a river (in which the father of the household had drowned). Thus using public transport to take the sick person to medical facilities would not always be possible.

4.2 Family structure

A total of 35 households were included in the study. Between them, they included 78 adults (18 years upwards) and 137 children (birth to 17 yrs). One hundred and twenty seven (59%) were female and 88 (41%) male, reflecting the pattern of male migration from the district (Demographics 2002). Sixteen families (46%) had no healthy adults in the household, and thus were "assisted child-headed households". A further five families had no healthy adults over 24 years old, and thus by Foster's definition (Foster 1997) were "adolescent-headed households". (Fig 6)

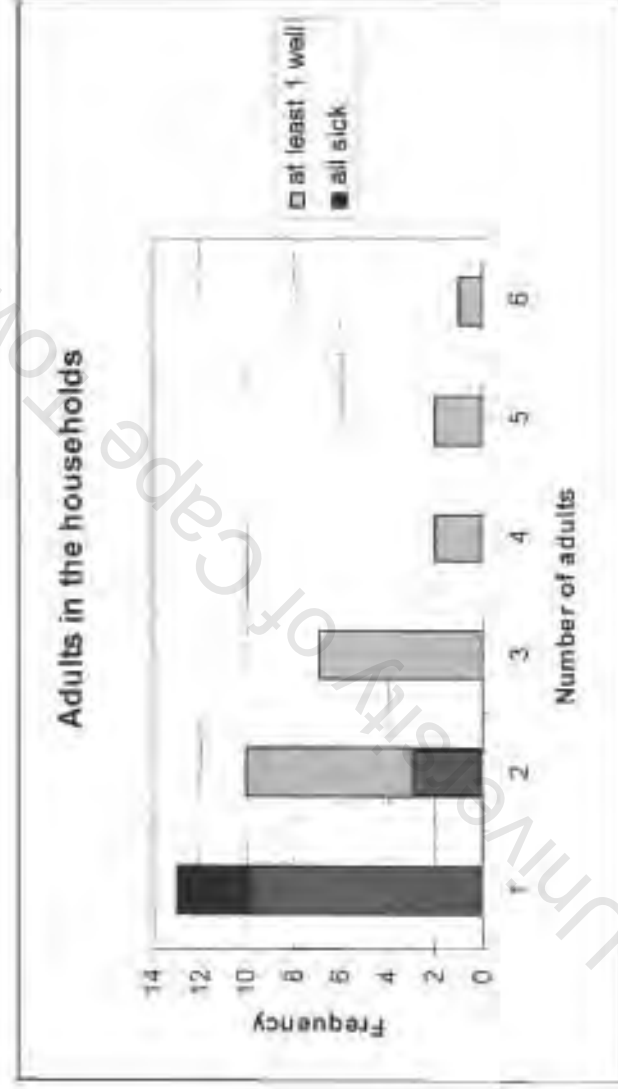


Figure 6: Adults in the households

The families included in the study were mainly nuclear families, typically one sick adult staying with three children. Others were three generational families, either with a parent of the sick adult living in the homestead, or older children in the family having babies of their own. The relationships of family members to the head of the household were as follows: six spouses, 124 children, three foster children, 27

grandchildren, seven parents, three siblings, nine other relatives and three non-related persons. In 27 of the 35 households (77%), the sick parent was identified as the head of the household. In the others, the head was either a parent of the sick parent, or in two cases, a spouse. The size of the household varied from two to eleven, with the median and mode being four.

The members of the households' occupations were described as the following; 26 preschool, 111 school-goers, 14 children not schooling though of school-going age, five self-employed (selling things), 12 unemployed and looking for work, eight staying at home by choice, five pensioners, 33 too sick to work and one alcoholic.

The majority of the children were aged 6-17 years, with the average age being 10.2 (Fig 7) There were three foster children living in the households. These children were orphans who had already lived through the death of their biological parents.

Twenty eight households (80%) had only one sick member, while six had two and one had three. Seventy five percent of these sick people were in the 30-59 age group, but there were also three young children identified as being chronically unwell. (Fig 8).

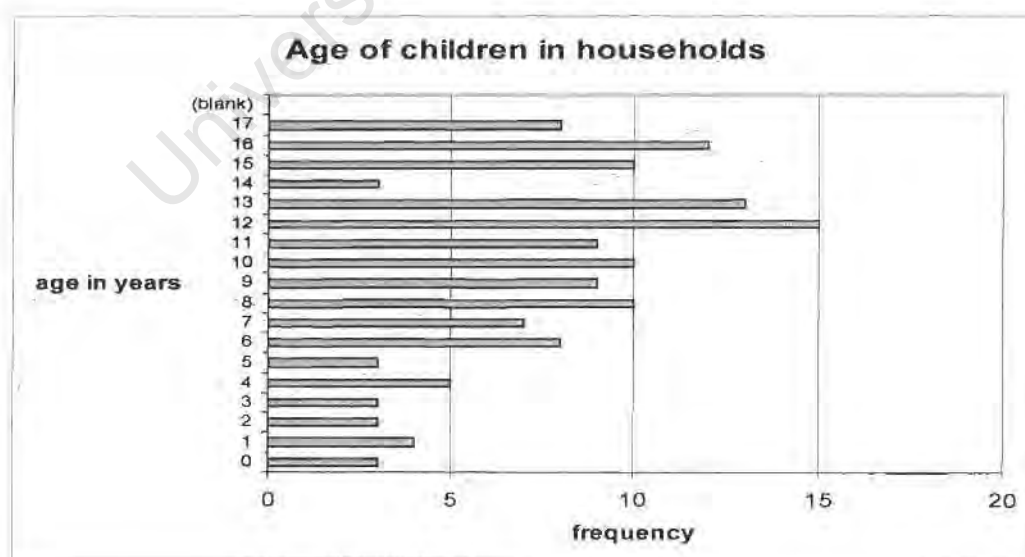


Figure 7: Ages of children in the households

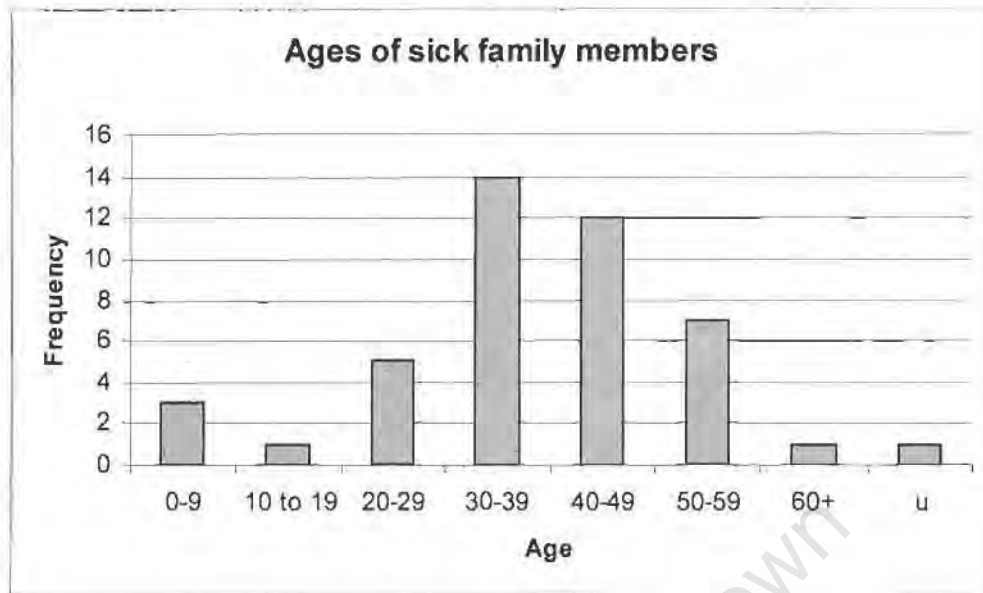


Figure 8: Ages of sick family members

Out of the 35 families, 16 (46%) had had one death in the household in the last three years, three (9%) had had two deaths, two (6%) had had three deaths and one (3%) had had four deaths. Other deaths were reported incidentally, but these were greater than three years ago. The majority of deaths were those of young children or babies of the now sick parent, but there were also many spouses and a few siblings who had died (Fig 9).

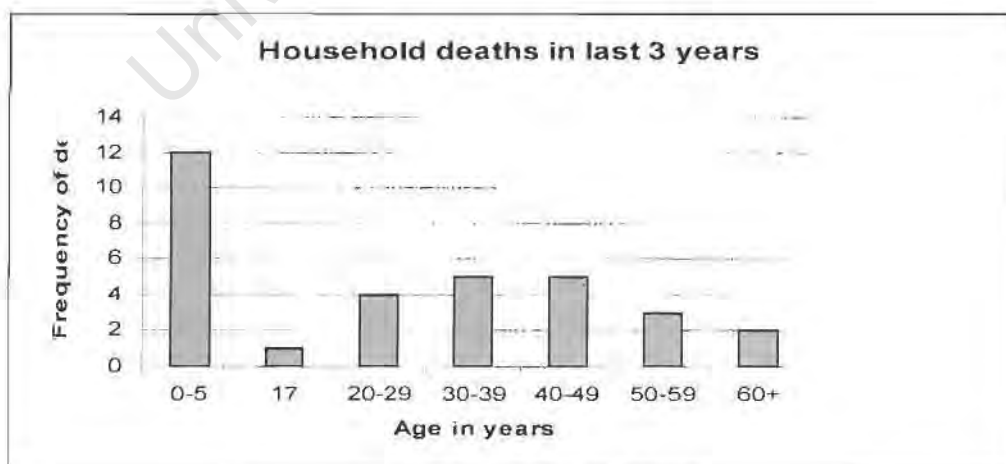


Figure 9: Deaths in the last 3 years

In seven families, there were a total of 14 children who were not attending school at all. Five families put this down to financial reasons, one child had spina bifida, and another stated that she did not want to go to school. Three children had moved away from three households, and attributed this move to the illness of the parent. These children were aged 12-14 years.

4.3 Profile of the sick parents

Twenty eight of the 35 parents (80%) reported themselves as having been sick and unable to carry out their usual work for more than a year, with 15 (43%) reporting sickness of greater than two years duration. Only two (6%) reported that their sickness had started in the previous six months. Eight sick parents were fathers (23%), while 27 were mothers (77%).

Almost all parents reported that they were able to wash, dress and feed themselves as well as walk short distances, go to the toilet, get out of bed and control their bowel and bladder. However, 12 out of 15 (80%) parents with whom the researcher kept in contact had died by the end of the study, proving that they had indeed been terminally ill, compared to only three (20%) she knew to be still alive. Indeed, several parents who were hospitalised requested discharge from hospital while they were still very weak so that they could go home to care for and protect their children. One father reported that he still went out to work in his fields even though he was too weak to stand- he sat on the ground and scraped at the earth with his fingers. He died a month after the interview.

Common symptoms included pain, weight loss and weakness. Most of the parents in the study had the clinical picture of AIDS with or without TB. (Table 1) Only six (17%) talked openly about their positive HIV status.

Pain was identified as the most problematic symptom in 15 parents (43%). Most complained that the pain prevented them from carrying out work or household tasks that they used to do such as ploughing the fields, fetching firewood and water. Four (11%) identified chronic diarrhoea as their most troublesome symptom. Reasons

given included that the parent needed to be carried to the toilet, or that it interfered with their ability to carry on as normal. A chronic cough was mentioned as the worst symptom by four parents (11%), although they could not clearly explain why. Other problems included paralysis and blindness in one woman, which left her completely dependent on her children; a teacher lost his job because of his chronic illness; one person with night sweats complained about his clothes always becoming wet; one woman had an itchy rash which made her life very uncomfortable. One woman was unconscious with gangrenous legs and close to death.

Table 1. Symptoms of illness experienced by the sick parents

Symptom	Frequency	
Weight loss	31/35	89%
Pain	29/35	83%
Weakness	27/35	77%
Chronic cough	15/35	43%
Night sweats	15/35	43%
Shortness of breath	15/35	43%
Diarrhoea (chronic)	11/35	31%
Confusion	7/35	20%

4.4 Child carers

Altogether 100 children were reported to be involved to some extent in caring for their sick parent. This varied from one to eight children per household. Of the 35 people identified as the main care givers, 60% were female. This reflects exactly that there were more females than males in the study sample (ratio fm 6:4). The youngest carer was only 4 years old; a girl who brought her mother cups of water to drink while she lay on her sick bed.

Twenty two (63%) of the main care givers were under 18 years, while another four (11%) were under 25 years (Fig 10). Usually the oldest child was identified as the main carer, but in one family an oldest sibling who was male did not take part in caring for the parent, but it was the next oldest sibling who was female. The main

carer, if under 18yrs, or child identified as most involved in caring for their parent, if an adult also was involved, was then interviewed. Eighteen (51%) of these reported that they sometimes missed school as a result of their parent's illness, either to care for the parent or for younger siblings. Sixteen (46%) reported that they no longer had time to play with their friends as they used to before their parent's illness. One reported that she could no longer visit her relatives.

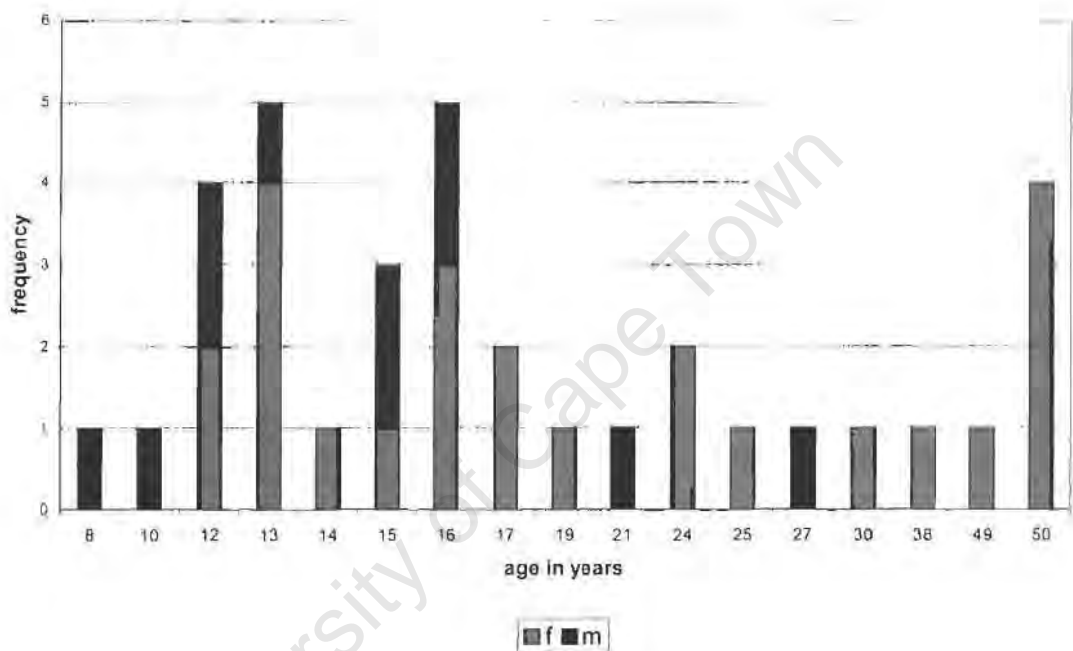


Figure 10: Age of main care giver

Nineteen child carers (54%) were also involved in trying to raise money for the family. Ten (29%) sold various things such as firewood, fruit and vegetables, others herded cattle, worked in fields for neighbours, cared for neighbour's children, made fences or did other piece jobs, while one reported that she begged for money from neighbours or relatives. One child was an 11 year old girl who did not go to school, but earned R50/month as a child-minder for a neighbour. (This has been found to be a standard rate for child labour by the orphan project.) This girl however was one of the few who said that she did not have any worries in life. Her mother died 2 months

after the interview. Other children reported that they only worked after school, at weekends or in the holidays.

The child carers were asked to explain how they dealt with various symptoms of their parent's illness. Their answers were as follows:

Dealing with pain:

Of the 35 children:

- Nine (26%) said they would give or recommend their parent to take pills
- Five (14%) said they would either take the parent to the doctor, or tell him/her to go for medical help.
- Five (14%) said they would prepare food and/or water for the parent
- Four (11%) described how they would help move the parent to a comfortable position or apply hot packs to ease the pain
- Four said that they would fetch a relative to help
- Four said they would do nothing
- One said she put sugar in her mother's eyes (the mother suffered from painful eyes)
- One said she felt sorry and wanted to cry
- One said that she prays
- One said that he tries to be obedient

Dealing with fever:

Of the 15 children whose parent's experienced fever:

- Three (20%) said they would sponge the parent with warm water

- Two (13%) said they would take the parent to the clinic
- Two said they would bring water to the parent
- Two said they would use traditional herbs to bring down the fever
- One said she would cook pap (maize meal).
- Five (33%) said they would do nothing

Dealing with diarrhoea:

Of the 13 children whose parent's experienced diarrhoea:

- Five (38%) said they would give oral rehydration fluids
- Two (15%) said they would give water or fluid
- Two said they would give traditional medicines *
- One (8%) said he would help the parent to go to the toilet
- One said he would dispose of the faeces
- One said she would take the parent to the clinic
- One said he would do nothing

Dealing with mouth sores:

Only one child was caring for a parent with mouth sores, and said that she used traditional medicines * to treat them.

* The use of herbal medicines is prevalent in Ingwavuma, and this was revealed in the responses of some children. Interestingly, it did not seem as if most families were making use of traditional healers, but they knew themselves, or were directed by relatives as to which plants to gather and how to administer them.

Knowledge of pills

Twenty five children reported that their parents were taking pills. Eighteen were able to name the pills that their parents were taking. Of these, 14 (78%) described the correct use for the pills while four children (22%) did not know what the parent was taking pills for. Six reported that their parents were taking TB treatment, while most of the others reported that they were using analgesics. Seven children (20%) did not know if their parent was on any medication, while in ten cases the parent was on no western medication.

Insight and concerns

Twenty five (71%) child carers said that they thought that their parent would get better (Fig 11).

Do you think your parent will get better?



Figure 11: Children's expectation of the parent getting better.

Thirty two (91%) child carers said that they did have worries. Some were anxious about more than one thing:

- Sixteen (50%) were worried about the lack of food in the household
- Sixteen (50%) were worried about the parent's sickness, and the fact that they might die.
- Five (16%) were worried about how to care for the parent

- Six (19%) were worried about their education, due to lack of money for fees or uniforms, or missing school to care for their parent.
- Three (9%) were worried about the future
- One (3%) was worried about caring for his younger siblings

When all carers were asked what the greatest hardship was for them at that moment, the following answers were given:

- Fifteen (43%) mentioned the lack of food and hunger as a main concern
- Ten (29%) mentioned the lack of money for school fees and uniforms
- Six (17%) said it was the parent's illness
- Two (6%) said it was the lack of someone to care for them
- One said it was the fact that their house was falling down
- One said it was the lack of opportunity to make money for the family

The child carers were then asked to list up to three types of help they would most like, if it were available:

- Twenty four (69%) asked for material support, such as food and clothes
- Twenty four (69%) asked for financial support to help them attend school
- Seven (20%) wanted help with caring for their sick parent
- Two (6%) wanted help with housing, as their houses were falling down
- One wanted a job

- One wanted someone to cook for the family

When asked how they felt about their future, 17 (49%) said "it is in God's hands", seven (20%) felt positive, five (14%) felt negative, one said she would be sad if her mother dies, two had not thought about it and three did not know.

4.5 Community support for the families

The family were asked about what help they received from neighbours, friends, teachers at their children's schools, church groups, nompilo and family members living outside the household. Overall about 80% of these people were aware of the parent's sickness with the neighbours and extended family being most aware, and teachers being least aware. Fig 12 shows the categories of people who were aware that there was a chronically ill person in the household, and indicates which of these were supportive towards the sick person in particular or supportive towards the household in general.

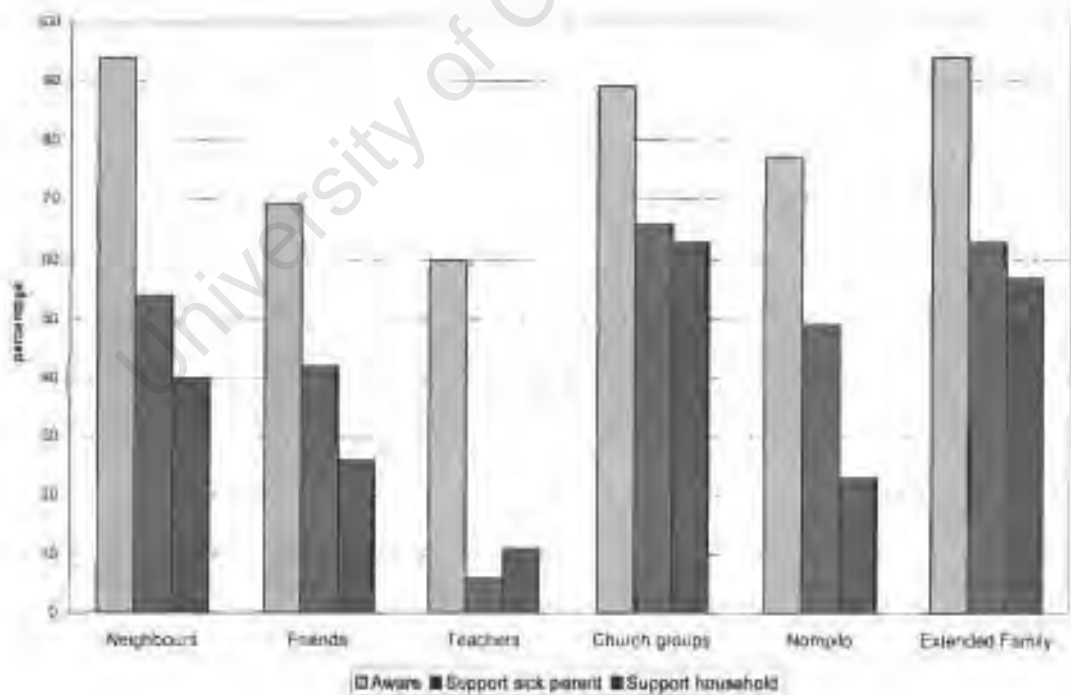


Figure 12: Support by different sectors of the community

Support given to households varied greatly. Some households received help from every sector of the community, while others received very little support or none at all. The majority of help given was described as “visits”. When asked to expand on this, “a visit” meant the visitor sat and talked or gave advice, and maybe smoked or drank tea with the family, but did not provide any material help or carry out any practical work at the homestead. In the case of the church groups, prayer was the most common form of support given.

The support given by the neighbours included visits (7), cooking or providing food (six), nursing the sick parent (three), prayer (two) and fetching firewood (one). On the other hand, one family reported that the neighbours would break in and steal their food (bought with money from a disability grant) while they were out. This household consisted of a sick father and two young girls who lived in a house that was falling to pieces. The mother and two other siblings had already died. The father was getting a disability grant with which he bought food. If he went away from the homestead to work in the fields, the neighbours could break in, just by sticking their arms through the gaps in the walls, and take the food. It did not seem that the neighbours were being deliberately cruel to this family because of the father’s sickness, but rather the neighbours themselves were desperately short of food too, and thus resorted to crime. Another sick father, when asked if the neighbours helped him replied cheerfully, “How can they? We are all starving here!”

The support given by friends included visits (two), cooking or providing food (four), ploughing the fields or helping with food gardens (three), fetching firewood (two), fetching water (two), giving money (one), helping with housework (two).

The support given by the few teachers included visits (two), waiving or paying school fees (two), and prayer (one). On the other hand, one teacher mentioned how naughty and disruptive one of the boys was in class. Even though she was aware of the social situation, she still put the boy in detention.

The support given by church groups included prayer (19), food parcels (two), money (two), cooking and nursing the sick person (one).

The support given by community health workers (nompilos) included visits (8), giving pills for TB (five), giving advice (two), giving bleach (one), giving food (one), giving gloves (one). The families reported that they did not generally feel that a visit alone was adequate support from the *nompilos*. It was noted that one TB patient did not receive DOTS as she should have done. Three families lived in areas where the *nompilo* was herself sick, and not working.

The support given by the extended family included visits (four), providing food (five), caring for the sick parent (five), caring for the children (three), taking the patient to medical facilities (two), giving money (two), gardening (two), guarding the house (one).

The extended family members who most often visited the households were more often female (25:13). The most frequent relatives (as related to the child carer) were grandmothers (eleven), aunts (seven), uncles (six), and older brothers (three). Visits varied from daily visits to only once a month. See Fig 13.

Nineteen households (56%) said that the extended family was happy to support them, while six (17%) said that they were not happy to support them and nine (26%) did not know whether the family was happy to support them. When asked for evidence for these answers, those who felt their family was happy to support them stated examples of how much support they had received, or that the relatives shared what little they had with them. Those who felt their families did not like to support them gave examples such as the fact that the relative only visited, but did nothing practical to help, visited only for a short time, never slept overnight at the homestead, or never visited. Those who couldn't judge the attitude of their relatives included families where the relatives lived far away or had no bond with them.

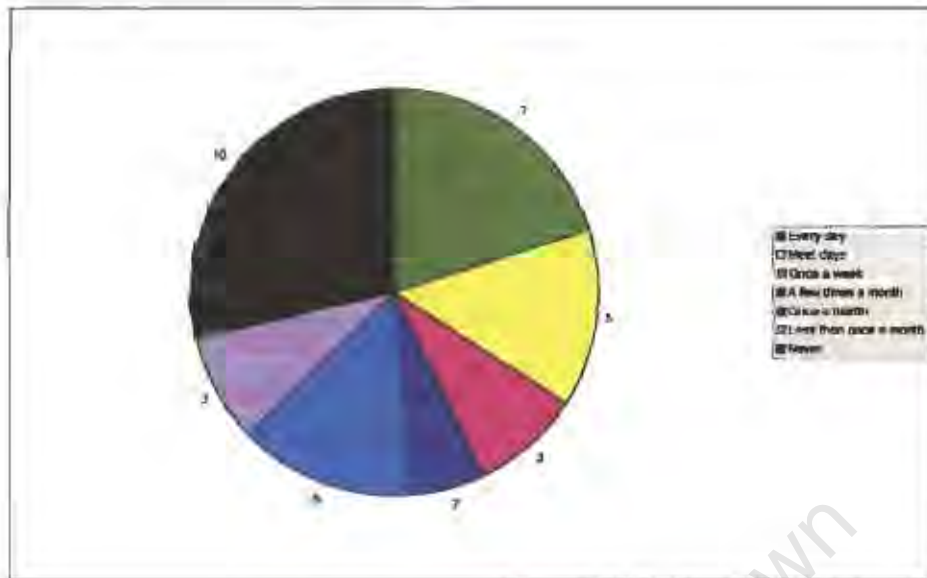


Figure 13: Frequency of visits from the extended family

Other organisations aware of the sick parents in these families included Ingwavuma Orphan Care (six), the Home Based Care Team (two) and the Department of Welfare (two). Ingwavuma Orphan Care was supporting the households with school fees for children, advice on accessing grants and food; the Home Based Carers were supporting the sick parent through nursing and training the carers in the family; the Department of Welfare was giving advice to one family about grants.

4.6 Discrimination against the children in the households

Only two (6%) of the households felt that the children were treated badly or differently because of their parent's illness. These children were scolded by neighbours or other children. One family reported that the neighbours shouted at them when they went to fetch water and told people to stay away from them because they were "contagious". The other family said that the other children did not want to play with them because their mother had AIDS.

In one of these households the mother had been open about her status for years, and had been receiving regular support from the hospital AIDS Team and orphan project. However, these support structures had not managed to alter the behaviour of the neighbours up to that point.

Chapter 5

DISCUSSION

5.1 Demography of households

The households in the study were clearly poor. Housing varied from dilapidated huts made of local materials to solid brick houses. On observation, several houses were in a state of near-collapse. Caring for a sick person in the best of conditions is difficult, but in these conditions must be quite a challenge, especially for the bed-bound parents and those with diarrhoea. The global lack of sanitation in Ingwavuma District fuels the spread of intestinal parasites, cholera and other infectious gastrointestinal disease throughout the whole population (unpublished observation). Those with weakened immune systems are particularly at risk of catching these diseases. Carers in turn, with close contact to sick people with diarrhoea, are at risk of catching infections from them as disposal of faeces and hand washing are difficult in these conditions.



Picture 1: Example of poor housing in the district

Fifty one percent of the families fetched water from sources within 15 minutes walk of their homestead at the time of the study. However, that was before the drought of 2002 started, and these water sources may not be available throughout the year. The only safe potable water in the district comes from the Shemula water scheme, but this scheme does not cover the whole health district. This water costs one cent/ litre, which is unaffordable for many of the rural poor (unpublished observation). Most people who buy this water use it only for drinking and cooking, and get the rest of their water from an unsafe water source which may be a greater distance from the homestead. Fetching water is a time and energy consuming chore, but is a way of life in rural areas.

Thirty seven percent of homes were more than thirty minutes walk from the nearest secondary school. Thus the older children in the household, on whom the burden of caring for their parent was resting, were commonly also faced with long walks to and from school. If the parent's condition deteriorated while the children were at school, it would also not be easy for him/her to contact the children. None of the homes or schools appeared to have land line phones. The stress brought on by going to school and leaving a very sick parent at home was mentioned by children at the National Children's Forum (Giese 2002a).

Seventy four percent of households were more than 30 minutes walk from the hospital or residential clinic. This would compound the problems of accessing medical care. There is only one ambulance to service the whole district, and this is not accessible to lay people. Hiring private transport to take a person to a health facility usually costs between R50-R300 which is a huge expense for people with little or no income. The residential clinics were not open 24 hours/day at the time of the study, so anyone requiring emergency treatment outside this time had to travel to the hospital up to 60km away. While clinic treatment is free, most people must pay at the hospital.

It was noted in the results section that many of the sick parents would be unable to access the public transport system even if their homestead was within 30 minutes

walk of a bus or taxi stop. Even those who could, would be faced with the limitations of the transport system; buses only pass by once or twice a day in each direction. It was not possible to reach all the homesteads with a four wheel drive vehicle, so sick people living in these homesteads would have great difficulty accessing medical care, needing to be carried or moved by wheelbarrow some distance to a vehicle.

Seventy four percent of families lived near a tuck shop. However, to get supplies of anything but the most basic commodities, the families would need to travel further afield. Tuck shops also tend to be more expensive than ones in bigger centres. The 25% of families who lived over 30 minutes walk from a shop would have to walk far to get even basic supplies. Thus shopping was shown to be another time-consuming and expensive activity for the family, stretching limited resources further.

5.2 Family structure

5.2.1 *Description of the family constitution*

In Ingwavuma District, it is common for adults under 25 still to be schooling and thus still be regarded as dependents or children (even though they may have children of their own). Therefore it is important to include these “adolescent households” in studies of “child-headed” households. Thus 21 households in the study were particularly vulnerable to the hardships that poverty brings, as well as being at risk of sexual or other abuse by outsiders. The lack of healthy adult males in these and other households would also put families at risk in this male dominated society. This issue of possible exploitation was not explored in this survey.

When teenagers or adolescents have babies, it is common for the grand-mother to do most of the child care; thus those babies would be as likely to suffer neglect as a result of their grandmother’s illness as would any biological young children of the sick parent. The increase mortality rate of uninfected children born to infected mothers has already been noted to rise by 2.4 to 3.6 times (Smart 1999, Wekesa 2000b).

The orphans found in the study households would be repeating a cycle of death and bereavement with the imminent death of their new guardians. This must have a bad

psychological impact on these children (Senegendo & Nambi 1997). Issues of placing orphans with sick relatives should be addressed to avoid the psychological distress caused by multiple bereavements. However, this problem cannot always be anticipated or avoided. The number of such children in this study was small, but the problem is likely to get worse as the AIDS epidemic worsens.

It should be noted that the findings on the make-up of the families in this study cannot be extrapolated to the population of Ingwavuma as a whole, as the study deliberately sought out such nuclear families. However, it can be seen that policy makers should not assume that the extended family still exists in all households in rural areas.

5.2.2 Economic potential of the households

In keeping with many publications (Drimie 2002, Booysen 2002, Donovan, Bailey, Mpyisi & Weber 2003) this study had found that there is a strong relationship between HIV/AIDS or chronic prime age adult illness and poverty, though it is beyond the scope of this study to say whether the sickness exacerbated poverty in these households. Lack of money contributes to the difficulty in accessing health services, as people must pay for transportation as well as hospital fees. It also adds to the hardship faced by the families with lack of food, lack of bedding and poor housing. Poverty leads to poor nutrition which may furthermore hasten the death of the sick individuals (UNDP 2002) and thus speed up progression to orphanhood for the children.

These families clearly require some sort of welfare service. While disability grants are available to terminally ill people, they are in reality difficult to access if the person concerned does not have an ID book or money to travel to town to apply for the grant. Child support grants are only accessed by 15% of those eligible in KwaZulu Natal, while foster care grants are accessed by 13.1% of those eligible (Children's Entitlement to Social Security). Improving the ease of access to welfare grants would greatly improve the quality of life of these and many other families and should be

regarded as a priority intervention by government and policy makers in combating the effects of the AIDS epidemic.

5.2.3 Sickness and death in the households

Six families had two sick members, while one had three. In these households, the problems of caring for the sick are multiplied, and scarce resources are further stretched. The burden of multiple sicknesses within a family must cause great hardship financially, physically and psychologically. It is undoubtedly a large burden for the child carers to cope with as they tried to continue their schooling, feed the family and nurse the sick family members. This was vocalised by a 13 year old at the National Children's Forum (Geise 2002b), "It is hard to look after a sick parent, younger siblings and try to be at school".

Three of the sick members were young children. These children would be at high risk of death whether they were HIV positive or negative, as it is unlikely that the child carers would know how to care for them, or be able to access the health care or nutrition needed. Overshadowed by the sickness of their parents, these young children would probably be neglected whether their illness was curable or not (Smart 1999). The fact that 12 children under five years old had already died in these households in the previous three years gives weight to this argument.

Two thirds of the families had already had one member of the family die in the last three years. Apart from the large number of children under five, the majority of these deaths were in the economically active age groups. These findings suggest that the deaths were likely to be due to AIDS. Multiple deaths in quick succession, especially of young adults are difficult for households, as there is little time to recover from the impact of one illness and funeral before another one occurs. As the bread winners die, those left behind descend into deeper levels of poverty (Drimie 2002).

The death of a child or parent from AIDS could be used as a risk factor for identifying vulnerable families in need of welfare support as one can see that it is

often the start of a train of deaths and ensuing misery for the rest of the family rather than just the end point of a chronic illness for that individual.

5.3 Profile of the sick parents

Most parents reported their sickness interfering with their parental duties for over one year. Thus they were dealing with a long term illness which would also be affecting their children for many months if not years. As discussed above, the nature of AIDS is a long drawn out illness with a fluctuating course. This can cause the patient and family to believe that the disease is cured, only to face another illness weeks or months later.

Most parents reported that they were able to wash, dress and feed themselves and most could walk short distances at least. Yet these people were very sick and dying. It is likely that in the harsh realities of their lives they were not able to adopt the “sick role”, but had to struggle on until they dropped dead. In families where there are no other adults, the sick parent may have to sacrifice their own health needs in order to care for their children.

Eighty three percent of the parents were suffering from pain. Chronic pain is a particularly distressing symptom, and was indeed identified as the worst symptom by 15 patients. Chronic pain can lead to sleep disturbance, mood swings and depression (UNAIDS 2000). The misery caused affects the children as well as the patient, as witnessed by the girl who said that she feels sorry and wants to cry when her parent is in pain. The hospice movement advocates that no one should die in pain, and drugs exist to cure every level of pain. However, only 12 of the 29 parents in pain were using any analgesics at all. Lydia Seburuya, director of clinical services at Hospice Africa Uganda says “oral morphine is very cheap, costing a few cents a milligram. It works. People’s lives are changed.” (BMJ News 2003) USAID Best Practices state that it is important that an HIV positive person has access to health facilities which will provide adequate pain relief as well as treatment of acute infections. Improved access to regular pain relief for these parents, for example through home based care, is clearly needed.

The symptoms of weight loss and weakness were also commonly noted. These symptoms are inevitable in most terminal illnesses, especially AIDS. Schroeder (2003) notes that malnutrition leads to immune suppression which hastens progression to AIDS, further weakening the body so that the person is unable to participate in food production. Thus a vicious cycle is entered. Dramatic results in improved health have been noted by the home based care team when people living with AIDS access government grants or are given high energy preparations such as Philani and EPap (Unpublished observations).

Chronic diarrhoea was a problem for 31% of parents. This is a difficult symptom in any setting, but particularly so in this poor rural environment without sanitation. It could be controlled by drugs (UNAIDS 2000), but again accessing these drugs would require an improvement in access to health care e.g. through home based care.

Confusion was noted in 20% of parents. This is likely to be a distressing symptom for the child carers, who still looked to their sick parent as an authority figure and head of the household right up to their death. These children would benefit from psychological support and guidance to help them deal with the parent's symptoms as is provided in Kenya (UNAIDS 2001, Lenya 2002).

5.4 Experiences of the child carers

5.4.1 Description of the children

While only the main child carers were interviewed for the study (i.e. 35 children), there were in fact 100 children involved to some extent in caring for their parents. It is likely that as the AIDS epidemic progresses, most children in the community will at some time be involved in caring for a dying parent or other relative. Indeed, the Medical Research Council (MRC) predicts that a third of all children under 18 will have lost one or both parents by 2015 (Bradshaw 2003). Children need to be given support and skills to deal with the situation. This has been done in Kenya through home based care (Lenya 2003) and Zimbabwe (Kaseka 2002) through kids clubs, but could also be included in the national schools curriculum under life-skills.

While there were more female carers than male carers, this corresponded to the proportion of males to females i.e. the same percentage of males were carers as females. This is an interesting finding in a culture where men generally do not get involved in domestic tasks or caring for sick people and has not been found in other African studies (Kelesitse 2000). These boys may have been ill-prepared for this role being thrust upon them, or they might have gained experience in the past caring for other sick relatives. Training programmes in caring for the sick should not be aimed at females alone, but acknowledge that males are also playing a significant role in nursing the sick.

5.4.2 Impact on schooling and socialising

Over half of the children reported that they sometimes missed school as a result of the parent's illness. Thus these children were experiencing a disrupted education even before they became orphans. This mirrors the situation found by the home based care teams in Phnom Penh, who described that in half the families they visit, children's schooling is suffering severely (UNAIDS 2001) as well as the study in Uganda (Drimie 2002) which found a 26% drop in attendance at school. Emotional problems caused by the sickness of the parent may further have interfered with their concentration when they were attending school (Hunter 1997). However the results show that only 60% of the teachers were aware of sickness in these families, and only 11% offered any support to the children.

A study of orphans in Ingwavuma (Clackerty 2001) found that the orphans were often mistreated by teachers when they came to school tired or hungry or could not concentrate. It is likely that the same is true for children caring for dying parents and siblings. A child at the National Children's' Forum (Giese 2002a) said "Children stop going to school because they don't concentrate when they think that they left parents in bed. They think that at any time they can die" Another reported, "I had to come home and look after the children, wash and clean and I do not do my homework. When I go to school I used to get beaten because my homework wasn't done." Missing out on school is not only be detrimental to the children's education, but also

means that they miss out on food provided by the school feeding scheme (at primary schools), which becomes an important source of food in poverty stricken families. Furthermore it will contribute to social isolation from their peers. Forty six percent of children are also isolated by the fact that many no longer had time to play with their friends. The two households which experienced open discrimination against the children would probably be the most isolated. These findings confirm the studies that children living with an HIV positive parent need as much support as orphans do (Beatson 2002, Alidri, Acidri, Mawejje & Ireland 2000, Fox 2002).

Fourteen percent of households had children who were not attending school for financial reasons. While these financial problems were no doubt made worse by the parent's illness, it may be that this statistic is no worse than in the general population of Ingwavuma. No data are available to confirm this, but many children can be found during the day not attending school. While the law states that children must not be excluded from school for financial reasons (South African Schools Act 84 of 1996, Section 5 (3)), the reality in Ingwavuma is that the governing bodies will not allow children to attend unless they have paid the school fees (of R25-R100 per year) and in some cases the children must also have school uniforms, books and pens (unpublished observation). Ingwavuma Orphan Care has been active in advocating for school fee exemption for needy children and is fully supported by the District Manager of Education. Yet the problem of children being thrown out of school or denied access to their school reports persists despite teachers being fully informed of the law.

5.4.3 Children as bread-winners

The average age of the children in the study was 10.2 years. Fifty four percent of children were involved in piece jobs to raise funds for the family. This mirrors the findings in Kenya (Nyambedha 2003) where orphans were making significant contributions to the upkeep of households. Orphaned children worked for relatively well off people in the villages who often underpaid them. They also engaged in income-generating activities such as burning charcoal, which divided their attention

between schooling and finding means for survival. No studies have been done to see what is the prevalence of children working in the community, and it might be that the study group is no different from the general population of Ingwavuma. However, the literature suggests that there is an increase in child labour in AIDS affected houses as a strategy to earn some income for the family (Drimie 2002).

The Convention on the Rights of the Child outlines in Article 32 “the right of the child from performing any work that is likely to be hazardous or to interfere with the child’s education”. Most of these children would be within their rights as their work was not interfering with their schooling, or detrimental to their wellbeing, but rather improved their quality of life through the money brought in to the household. However the 11 year old girl working for R50/month was having her rights violated, no matter how content she was with the situation. Ingwavuma Orphan Care has since intervened and made sure that she started school in the new school year.

There is clearly a role for Ingwavuma Orphan Care to play in advocating for vulnerable children to avoid exploitation. While the children should be encouraged to engage in entrepreneurial skills and income generation as part of learning new life skills, care must be taken to see that they are not exploited. The Children’s Institute, Cape Town, argues that we should work towards a society in which children do not have to do any form of work in order to survive. Those who are forced to work for survival should be provided with support in order to ensure their work does not harm their education and development (Giese 2002a).

5.4.4 Children’s ability to care for their parents

The majority of the child carers dealt appropriately with their parent’s symptoms. Some showed good knowledge of health care, such as being able to describe in detail how to make up and administer oral rehydration fluids, or how to sponge down a parent with a fever. Others said they would call for help or take the parent to a health care provider.

Those families who were being treated by traditional healers were largely excluded from the study because treatment involves the patient staying with the healer for long periods, and thus they were not being cared for by their children in their own homes (unpublished observation). This survey is not in a position to judge whether traditional remedies were likely to be beneficial or harmful. However, as these treatments are free and readily available, they provided a more accessible solution to the parents' illness than did the government health service, so it is hardly surprising that these remedies were used by at least some of the families.

Five children said that they would prepare food or water for a parent in pain, while one would do the same for a parent with fever. While this may not be of direct medical benefit to the parent, it would be an action demonstrating love on the child's behalf, and make the child feel that he/she was doing something useful. At the same time it could improve the nutrition or hydration of the parent as well as making them feel cared for. Thus it would help the parent physically and the family psycho-socially.

A significant minority of children said they would do nothing. They were not asked why this was. However, it could have been because they did not know what to do, or did not see it as their role, or felt helpless or were not aware of the parent's symptoms. The feeling of helplessness comes out in the children's responses who said they "would pray", "feels sorry and wants to cry" and "tries to be obedient".

Most but not all of the children whose parents were using western medication knew the names and usage of those pills. It is important that the child carers have this knowledge, particularly if they are the sole carer of the parent.

It seems clear that the children would benefit from support and guidance when it comes to caring for their parents. At times they were putting their own health at risk e.g. by lifting an adult heavier than themselves or by disposing of potentially infective faeces. In some instances they may have been doing harm unwittingly to their parents e.g. by putting sugar in a mother's eyes to ease her pain, or by giving potentially harmful herbal remedies. The need for practical nursing assistance for such children

was also noted in Zimbabwe by Foster & Beatson (1997) and is likely to be found throughout sub-Saharan Africa. Those who felt helpless could be assisted by a trained carer coming alongside them and teaching them some basic nursing skills as is done in Nairobi (Lenya, Dimba, Aduwe & Odiembo 2002), where children are involved in pain control, continence care and even intravenous medication. However attention must be paid to the children's rights to make sure that they are not exploited or left unsupported in this role.

5.4.5 The children's worries and perceived needs

Seventy one percent of the children said that they thought that their parent would get better. This contrasts with the Ugandan study (Sengendo & Nambi 1997) where 49% of children living with a very sick parent expressed fears that their parent would die. However, this response might have been due to the way the question was worded in Zulu which implied the sense "do you hope that your parent will get better". Those who said "no" tended to be those with the sickest parents, or older children who had more insight into the situation. The fact that 16 children were worried about their parent's sickness and the possibility of them dying suggests that they did not really believe that their parent would recover. These children would benefit from open counselling and preparation for the parents' death as is done at other sites (Nyamayaro 2000, Beatson 2002)

The National Children's Forum (Giese 2002a) allowed vulnerable children to express themselves and their fears. Similar needs were found to this study, although they were not ranked in order of severity. The Farm orphan support trust in Zimbabwe identified different fears among child-headed households. These children's commonest fear was losing their home. Others were worried that they would live the rest of their lives in poverty and that their lives would become more difficult in the future (Walker 2002). The Zimbabwean children thus generally seem to have had a longer term outlook on life despite also living in extreme poverty. No other studies have been found which look at global perceived needs of the child.

As many children were worried about where their next meal would come from as were worried about their parent's sickness. Overall the lack of food came up as the main concern for the children. This concern was also identified at the National Children's Forum: "I do not have a mother. I stay with my grandmother and father. At home there is no food most of the time. My grandmother and father do not have any money. My father is sick. I need food." (Giese 2002a) This again highlights the severe poverty faced by the families. In the struggle for survival, immediate needs such as food often outweigh longer term ones such as the parent's imminent death.

Worries about finances for schooling also ranked highly. This concern may have been inflated by the timing of the study which took place from November to February; the time of year when families must find funds for school fees and uniforms or risk the children being thrown out of school for that year. This was also found at the National Children's Forum; "My mother is not working. She has got HIV and my little sister has got it too. I am worried because I have not paid school fees in the last three years. I am sent back home every time they want school fees and I do not have." (Giese 2002a) However, exclusion from schooling is a violation of these children's rights, as well as against the law, and contributes to the stress felt by the children.

Nineteen percent of children found their parent's illness their biggest problem. This answer might have been inflated by the context in which it was asked; the children were aware that this was a study concerned with the parent's illness. However, it is probable that children would indeed be concerned about their parent's sickness, as the parents were all very ill and many children had seen other family members die.

Two children found it hardest that there was no one to care for them. These children were obviously struggling with the adult caring role being thrust upon them, and wished that they could continue to remain children and be nurtured for longer. Again, these children's rights were being violated, though it is unfair in this resource poor setting to blame any particular party for not being able to meet these children's needs.

One child mentioned the house falling down as the biggest problem. Housing was very bad at several homesteads, as most homes were made out of traditional material and need regular repairs and maintenance to stay water tight. The lack of money and healthy adults in the preceding year(s) would have prevented this maintenance taking place. Thus families are not only faced with orphanhood, but being left with a disintegrating building as their inheritance as has been described elsewhere the literature (Smart 1999, Hunter & Williamson 1997). Few relatives are likely to want to move in to such homesteads as foster parents, so these children face being moved and losing their family ground, or living as child-headed households in inadequate housing. This is a problem for which Ingwavuma Orphan Care is trying to find a solution.

One child, a teenage boy, mentioned the lack employment opportunities as his biggest concern. He had already taken on the feeling of responsibility to care for the family, and was now faced with the problem of how to provide for them. The high rate of unemployment in Ingwavuma contributes to feelings of helplessness and despair in youth in general in Ingwavuma.

5.4.6 Support requested by the children

The majority of children requested material and financial support for survival and schooling. Again this shows that poverty leads to hardships which even outweighed their parent's illness. These answers may also have been given because the children were aware that Ingwavuma Orphan Care or the Department of Welfare could provide such help.

Seven asked for help in caring for their sick parent, while another wanted someone to cook for the family. This was also found at the National Children's Forum (Giese 2002a) where a child expressed herself thus; "I want someone who will look after my grandmother while I am at school. You don't have money to help her when she is ill. I wish we can get help from the government." This type of help could be provided for by the community, as it requires no financial input. Support for sick parents could also be provided by an expanded Home Based Care project.

The fact that one child wanted a job shows that not all families wish to become dependent on the state or NGOs or want hand-outs. This boy clearly wanted the opportunity to support his family himself.

5.4.7 Perception of their future

The majority of children said that their future was in God's hands. Many people in the district are church-goers and have a belief in God. In a setting where people live from hand to mouth, and don't always know where their next meal is coming from, people do not generally make plans for the future. Thus this answer was to be expected.

It is remarkable that 20% of children felt optimistic about their future, despite the harsh conditions that they were living in, and the likelihood of becoming orphans. This is a higher percentage than was found in the Ugandan study (Sengendo & Nambi 1997) or in the FOST study (Walker 2002). This may indicate that the children lacked insight into the bleakness of their condition, or else were very positive and could always see the good in every situation.

5.5 Community support for the households

All sectors of the community were more supportive of the sick parent than of the children or household as a whole. This confirms the findings of Mehra, Sakhuja and Panwar (2002) that services are geared to the needs of adults not children. The only exception to this was Ingwavuma Orphan Care which focused its care on the children, but this organisation was only involved with six of the households. Children are emotionally vulnerable, and the younger children also in need of physical support such as with being fed, washed, dressed during this time when their parent is too ill to care for them. The study revealed that only around 25% of the children were receiving this sort of support. The study did not quantify the amount of support received (except with regards the extended family), so even those getting support were not necessarily receiving help on a daily basis.

It may be unrealistic to expect such a poor community to be able to provide significant support to these families. The FOST study (Walker 2002) reported that even where there are community initiatives to help child-headed households these are breaking down under the severe economic hardships and food shortages being experienced by all elements of society. Russel and Schneider (2000) comment that in the South African context too there are limits to whether communities can be expected to be self reliant and to absorb the impacts of AIDS without external assistance. This is likely to be true for the community of Ingwavuma where food security is a problem for the wider community (Schroeder 2003).

It was interesting to note that quite a few families reported that they did not have any friends. This may be because they classified "a friend" in one of the other categories e.g. neighbour or church member. Alternatively, friends may have deserted the family when they saw that the parent showed signs of HIV infection. Further research would need to be carried out to investigate this.

As expected neighbours and relatives have most frequent contact with the households, whereas teachers working in overcrowded schools might well be unaware of the social situation of each learner in the class. The fact that 40% of teachers were unaware could cause problems for the children if they missed school, could not pay school fees or were not performing well at school as the teacher would not understand why (Giese 2002a, Clackerty 2001).

Only 15% of the households received help with nursing the sick parent. The bulk of the nursing was therefore mostly done by the main carers, 63% of whom were children under 18 years. This cannot be considered an acceptable situation in any society, especially given the fact that the age of the carers was so young, and the children sometimes felt helpless or unable to help their parent. It is also unconstitutional, the South African Constitution stating "Every child has the right not to be required or permitted to perform work or services that are inappropriate for a person of that age (Section 28 (1)f). Again, there is a gap seen between policy and reality in Ingwavuma.

While active in spiritual support, most churches did little to help the families practically, with only 5 families receiving practical help from them. Only one family described regular support by way of church members coming to cook for the family and nurse the sick patient. While prayer and visits might help the family socially and spiritually, this kind of help does not meet any of the needs expressed by the children. Even though local church goers are often poor themselves, there are many ways they could support these families such as caring for the children, cleaning the house, fetching firewood and water without having to spend any money. The Christian tradition is one of caring for the sick, widows and orphans (James 1 v.27) but this is not really occurring in a situation where it is desperately needed.

The *nompilos* mostly visited the families once a month as part of their routine visits. Five visited more frequently to give TB treatment. Only two provided nursing support by giving gloves or bleach, while one gave food, maybe from her own pocket. It can be seen that the *nompilos* are not carrying out a significant amount of home based care in the district, even though many have been trained to do so. This is unlike the situation in Zimbabwe (Walker 2002) where Farm Health Workers were found to be one of the main source of general help to child-headed households. However, there is no system in place to support the *nompilos* in this role. Instead their emphasis is on primary health care and prevention. The function of the *nompilos* in the district is currently under review by management staff, given the clear and growing need for Home Based Care.

Out of the extended family, the support of these households mainly fell on female members, especially the grandmothers and aunties as would be expected in African culture. However, one third of carers in this group were male, so their role should not be ignored. One third of family members visited most or every day, and thus might have been providing significant support. One third visited between once a week and less than once a month, while another third never visited. Thus two thirds of the households were receiving minimal to no support in the day to day struggles of the household. This situation seems to be slightly better than the support found to be

given to child-headed households by Foster, Makufa, Drew & Kralovec (1997) in Zimbabwe. However the study households might be expected to receive more help as they were facing terminal illness not just every day problems. However, only 56% of the families felt that their relatives were happy to help them. Thus some who received visits got the impression that the extended family was visiting grudgingly and not really wanting to help them. It can be seen that the extended family was generally not providing the support that these vulnerable households required. This finding does not support the argument that child-headed households are a natural evolution of the extended family (Foster, Makufa, Drew & Kralovec 1997) in which while living separately, the children are supported by the wider family or clan structure. It rather agrees with Nyambedha, Wandibba & Aagaard-Hansen's (2003) findings in which there was a lack of significant participation of the extended family.

The Home Based Care project was involved in two of the households. This project started in February 2002, and only covers 4 small areas in the health district. Trained home based carers visit households on average twice a month bringing them comfort, advice on caring for the patient as well as nursing supplies and drugs. Where this service existed it was seen to be greatly appreciated and made a significant difference to the families supported by it. There is a clear need to expand these services to as much of the district as possible.

The Department of Social Development was found to have visited two families. There are only three social workers in the district, with one vehicle between them. Their services are stretched so it is surprising to find that they had visited any of the families in the study. The advice given by the social workers was appreciated by the families. The Department of Welfare is badly understaffed, especially given the severe poverty in the district. Thus it confirms Gow's view that there is a yawning gap between policy formation and implementation of both the Government Strategic Plan and the food security policy. This is despite the deficiency of government services in Ingwavuma being widely published in the Sunday Times (2001) and Carte

Blanche (2001). There is a need for ongoing advocacy and motivation by NGOs and local government offices to increase the number of social workers in the district.

5.6 Problems caused by the community for the families

It was encouraging to find that in only two households were the children experiencing discrimination as a result of their parent's illness. One sick father, when asked if the neighbours helped him replied cheerfully, "How can they? We are all starving here!" This again points to the context in which the study took place. While one can see the suffering and hardship faced by the study families, it was not necessarily worse than that faced by those around them, apart from the additional difficulties caused by the sickness. Those families receiving disability grants would possibly be better off financially than their neighbours (Schroeder 2003).

Children going through the trauma of their parents' death are likely to have emotional problems which can manifest as misbehaviour or inattention at schools. Yet the teachers feel overwhelmed by the need to maintain discipline in overcrowded classes and are unlikely to be sympathetic to such displays (Giese 2002b, Clackerty 2001). There is a clear need for sensitisation and support for the teachers so that they in turn can support their learners. This is now being carried out by Ingwavuma Orphan Care. In Zimbabwe, where the Farm Orphan Support Trust had carried out training with teachers on psycho-social support for orphaned children, it was indeed found that children did not experience discrimination at schools despite behavioural problems exhibited by some children (Walker 2002).

5.7 Limitations of the study

There is no database or directory of the homesteads in the health subdistrict. The methods used to identify families for the study bias the selection in favour of better known, more accessible or more vocal households. The method of identification would also bias the responses as to who is providing community support. Thus families identified by community health workers would be more likely to say that their community health worker is supporting them; those identified by schools would say that their school is aware of them, and those identified by the orphan project

would say that this project is supporting them. By using several sources to identify families, it was hoped to get a more diverse and representative group than would have been achieved using only one source. However, the sample interviewed may not be a true representation of the households caring for terminally ill parents throughout the health district.

The sample size of 35 was fairly small, but should give some indications of issues faced by the children in Ingwavuma District. The original target of 50-100 families could not be reached due to time constraints. The study tried to be qualitative rather than purely quantitative. The results cannot be extrapolated to represent all South African children caring for sick parents but may give indications of problems faced in similar rural undeveloped areas.

It is impossible to define and predict who is "terminally ill" just by looking at and talking to a person. Indeed terminally ill is a rather vague term without a definite definition with regards timeframe of impending death. While the researcher was medically qualified and familiar with treating patients with terminal illnesses, it would be impossible to predict accurately the course of disease in each sick person. Thus while at least twelve of the parents had died within three months of being interviewed, others were still alive a year later. The study may rather be viewed as looking at children caring for parents with a chronic debilitating illness which is likely to result in premature death.

Some of the children were shy and not used to expressing their thoughts to adults. The presence of a white researcher may also have made them shyer. All efforts were made to put the children at ease, but they may have faced some problems and worries which they did not express in this study. For example no mention was made of sexual abuse which is thought to be widespread in the area. Further qualitative research could be carried out in order to explore these issues further.

The questionnaire did not ascertain the income of the household or the numbers of children and adults who were accessing the grants that they were entitled to. This

would have been valuable information in assessing the economic vulnerability of the households. However when consulting local staff and researchers over the study design, it was advised that this information was too sensitive and questions about income and grants would be unlikely to yield accurate information. The same is true for information on exploitation and abuse of children by community members. Such information might be better elicited through other techniques such as small group discussions, role play or story telling with the children.

The questionnaire was written in English while the interviews were conducted in Zulu. This may have lead to inconsistencies and inaccuracies in translation by the three different field workers. It would have been preferable to translate the questionnaire into Zulu and cross-validate the translation with back translation in order to improve the accuracy of the interviews. However, there would have been greater time and resources needed to do this then record the answers in Zulu and then translate these into English at a later date. As the researcher had a reasonable understanding of Zulu, it was felt that the method used was acceptable.

Chapter 6

CONCLUSIONS

Socioeconomic conditions

The impact of poverty on the family's life should not be underestimated. In fact the child carers often identified their greatest hardships as lack of food, money for schooling and poor shelter rather than their parent's illnesses.

The dying parents

These very sick individuals did not take to their sick beds and expect to be nursed, but rather carried on trying to function until they literally could not go on. Those living alone with young children probably felt they had little choice but to struggle on to the end.

Children's ability to care for their parents

The children in the study generally seemed to be doing a good job of caring for their parents within their limitations. While few children requested help in caring for their parent, it is clearly unacceptable for children to be left unaided to care for a dying parent. This study has highlighted the reality of the situation in these households and the need for children to be trained and supported as care givers.

Effect on schooling

Caring for a sick parent interferes with school attendance. While 60% of these households said that the teachers were aware of the parent's illness, only 11% of the children received any sort of support from the teachers. Thus child carers are not only struggling at home to nurse their parent and survive themselves, but also face an unsupportive environment at school. Further stress is placed on the children by the teachers' refusal to acknowledge the Schools' Act.

Support from extended family

It cannot be assumed that relatives will continue to shoulder the burden of caring for sick family members, or that support given even at present is adequate. Any attempts at home based care programmes must assess the relatives' willingness and ability to care. The "safety net" of the extended family does not appear to be as strong as might have been predicted.

Support from the wider community

While the majority of different sectors of the community were aware of sickness in the study families, support provided for the families was mainly limited to visits. Again policy makers and government cannot assume that "the community" can shoulder the burden of caring for terminally ill patients, particularly in families as vulnerable as these. Furthermore, what support was offered was mostly aimed at the sick parent. The children's needs were neglected for several reasons. Firstly their needs are overshadowed by the sickness of the parent in the household, and the household's efforts may be focused on trying to keep the parent alive as long as possible. Secondly, as they are not yet orphans, the children do not fall into an easily recognisable category for welfare support. It would be difficult to quantify how sick a parent must be before the child needs help. Thirdly it is often assumed in African culture that children have no need to express feelings and do not experience emotional trauma so do not need to understand what is happening when their parent is dying. There is a clear need for greater community awareness and provision of support specifically to these children to meet their social, material and psychological needs.

Access to services

While these families were in great need of health and welfare services, they were to a large extent unable to access them. Government services on the other hand also lack the resources to reach out to the people who most need them. Ingwavuma Orphan Care and the Home Based Care project are also too small and under funded to reach all the potential clients in the district. Comprehensive care in the community is not

happening in Ingwavuma District. Urgent funding and resources are needed to improve service provision

University of Cape Town

RECOMMENDATIONS

7.1 Poverty alleviation and community development

1. **General poverty alleviation measures.** Improving the socio-economic conditions found in Ingwavuma would go a long way to improving the quality of life of these families. Better infrastructure would aid access to health care, schools and shops while more disposable income would improve nutrition, housing and access to better education.
2. **Better sanitation in the district.** Each homestead should have at least a pit latrine. This will aid in nursing of patients with diarrhoea as well as reducing the spread of infectious diseases throughout the district.
3. **Business skills training targeting vulnerable families** Households which have lost or are losing their economically active members, should be targeted to learn new ways of making an income. People who were not traditionally the breadwinners may need to take on this role e.g. the oldest sibling, unmarried mothers or grandparents. The Dynamic Business Start-up Project is working in the district, and could start training people from such families.

7.2 Coordination and strengthening of services

4. **A multi-sectoral approach is needed.** If all government departments, NGOs, CBOs and the community take part in supporting affected families, the load will be spread and more holistic care will be given. The Integrated Plan for Children infected and affected by HIV/AIDS needs to be urgently translated from paper to its implementation stage. Ingwavuma District has

few NGOs and CBOs working in it, and there is a need to bring in new organisations as well as strengthen existing initiatives.

5. **Improved access to government grants.** All families who are entitled to government grants should be able to access them. The service by Home Affairs must be improved so that all members of society can get identity documents. The community must also be taught the value of these documents and keep them safe. The Department of Welfare must have the capacity to process and monitor the grants. The frequent cancelling of all disability grants followed by the need to reapply causes great stress on the limited resources of the Departments of Health and Welfare as well as confusion and misery for the disabled and dying.
6. **Home based care-** this intervention clearly needs to be extended throughout the health district. The project will then be able to support the child carers and train them to provide meaningful help to their parents as well as relieve them from some of the burden of caring. The nurse who runs the project is able to bring drugs to the homesteads and as such would be able to provide treatment for the pain that so many of the parents were experiencing. While money has been targeted for HBC by the Department of Health, the District Health Service has not been given any clear directive how to access this money to date.

The home based carers in conjunction with staff from Ingwavuma Orphan Care should also help the children to prepare for their parent's death. This can be done through counselling and the use of memory boxes. Practical needs such as applying for birth certificates and appointing guardians will also help ensure ongoing care is provided for the children once their parent has died.

7. **Need for greater numbers of social workers in the district.** The three social workers are not able to support the hundreds of families in the district

in need of assistance. There is a clear need for more social workers, whether these are employed by the department of welfare or NGOs operating in the district. These would be able to speed up the processing of disability grants for sick parents, followed by foster care grants when the parent dies. They would also be able to counsel families going through stressful conditions and provide them with advice on accessing additional support, whether from the extended family or NGOs.

8. **Greater awareness in schools** of the social problems faced by learners. Teachers and governing bodies must be made aware of the social problems facing many of their learners. The Department of Education should come up with strategies for supporting children going through bereavement to orphanhood. Ideally there should be some psychological support for the children. This could be provided in Ingwavuma by the Orphan Care Project, and by peer groups in the schools which are supported by the School Support Project.

The problem of children being excluded from school if they have not paid their school fees must be addressed urgently as this is a factor causing additional stress among the children and directly goes against the Schools' Act. The School Support Project, which is funded through Friends of Mosvold Hospital, as well as Ingwavuma Orphan Care are trying to address some of these issues. However the Department of Education at a local level should be taking the lead in improving access to education for orphans and vulnerable children rather than doing so only under duress when NGOs inform the community of their rights and the law.

7.3 Support of families and children

9. **The Government** should introduce a package of antiretroviral treatment and care for infected parents. This would prolong the life of the parents and thus allow the children to remain in their role of childhood for longer.

10. **Churches** should offer more support for the sick. As well as visiting and prayer, church members should be encouraged to provide practical support such as doing some household chores or gardening, or provide food where needed. Local churches could pair up with more affluent city churches of their denomination so as to get the financial back-up that they might need for providing more practical support to these families.
11. **Neighbours** should be commended for their good work and encouraged to continue supporting each other. Communities need to be strengthened so that they can care for their sick. While the willingness may be there, the resources are not. Support could be provided through training in home based care, and setting up local support centres where communities can liaise with other care providers.
12. **NGOs** should offer training to children to develop skills in caring for the sick and younger siblings as well as improving their income generating potential. They should also play a role in advocacy to make sure that the children's rights are being met.

7.4 Further research

There are many issues which need to be explored further. These include :

- the extent of child abuse in the district, particularly among these vulnerable children
- the psychological impact of multiple bereavement on children affected by AIDS
- the knowledge, attitude and behaviour of teachers to children affected by HIV/AIDS
- the quality and quantity of help provided to families by the community

- the capacity of the community to care for its sick
- factors influencing how much support families receive
- what happens to the children immediately after their parents' death and then in the medium and long term.

University of Cape Town

REVIEW OF KEY ISSUES

1. The setting of this study was a poor rural area with minimal infrastructure. The households studied generally had poor housing, poor access to clean water and sanitation, poor access to public transport, shops, schools and health services. This setting compounds greatly the problems encountered in caring for sick people.
2. The families studied were generally very vulnerable. Apart from the terminally ill parent, half the families included no other adults, while four others only had a young adult (under 25 years). Only approximately 60% of families received support from their extended families or communities and this support was often limited to social visits with little material or practical input to the households.
3. Dying parents were sometimes found to be struggling on to their end, trying to maintain the household until they collapsed. There was little help available for these parents to relieve them from pain, weakness or diarrhoea. However, many children were involved in nursing their parents and often used appropriate interventions.
4. The households studied had little potential to become self-sufficient, even if better job opportunities existed, as most had no members actively seeking work but consisted of sick parents, aged grandparents and school-going children. Such families need input from welfare organisations to reduce poverty and hunger.
5. Males as well as females were found to be involved in caring, both as main carers of the sick and also by providing support such as money,

transportation to hospital and social visits. Caring for the sick should not be viewed as a female role.

6. The child carers saw poverty and its related consequences as their greatest hardship. This even overshadowed the stress and sadness of caring for a dying parent. Lack of food, lack of money for school rated higher as hardships than did caring for a sick parent.
7. Half of the child carers reported having to miss school sometimes as a result of their parent's illness. Others were worried that the lack of money for school fees and uniforms would result in them being thrown out of school. Only 11% of teachers of these children did anything to help them. The law which states that all children between 7 and 15 must attend school is being ignored by many schools in Ingwavuma.
8. Most of the families studied were affected by AIDS. Yet there was not much evidence of discrimination against these families by the community. However 6 out of 35 households stated that their relatives were not willing to support them. It cannot be assumed that the extended family can or will provide adequate support to all vulnerable families in the district.

REFERENCES

- Ainsworth, M., Beegle, K. & Koda, G. (2002) AIDS and primary school enrolment in northwestern Tanzania. *AIDS 2002 Conference paper, Barcelona.*
- Alidri, P., Acidri, J., Mawejje, D. & Ireland, E. (2002) Improving psychosocial support for HIV/AIDS infected/affected children: What do Ugandan children have to say? *AIDS 2002 Conference paper, Barcelona.*
- Ankrah, E. (1993) The impact of HIV/AIDS on the family and other significant relationships. *AIDS Care* 5 (1) 5-22.
- Beatson, R. (2002) Traditional attitudes to children and the psychosocial impact of AIDS on children in Zimbabwe. *AIDS 2002 Conference paper, Barcelona.*
- Bicego, G., Rutstein, S. & Johnson, K. (2003) Dimensions of the emerging orphan crisis in sub-Saharan Africa. *Social Science & Medicine*. 56(2003) 1235-1247.
- BMJ News roundup(2003, 8 November) Africans are dying of AIDS without pain relief. *BMJ* 2003(327)1069.
- Booyesen, F., van Rensburg, D., Bachmann, M., Englebrecth, M. & Steyn, I. (2002) The socio-economic impact of HIV/AIDS on households in Southern Africa. *AIDS bulletin*. Vol II, No.1.
- Bradshaw, D., Johnson, L., Schneider, H., Bourne, D. & Dorrington R. (2002) Orphans of the HIV/AIDS Epidemic. *MRC Policy Brief* No.2 May 2002.
- Buhendwe, L., Zachariah, R. & Labana, S. (2002) Role of communities in care and support to people living with AIDS in Tyolo, Malawi. *AIDS 2002 Conference Paper, Barcelona.*
- Burman, S. & Fuchs, R. (1986) When families split: Custody on divorce in South Africa. In S. Burnam & P. Reynolds (Eds.), *Growing up in a divided society: The contexts of childhood in South Africa* (115-138). Johannesburg Raven Press.
- Butuuro, D., Tumusiime, A., Denyonga, M. & Kaddu, A. (2000) Counselling and home based care. *AIDS 2000 Conference paper, Durban.*
- Children's entitlement to social security (2001) *National Consultative workshop, March 2001, Cape Town.*

Clackerty and associates (2001) The role of stigma and discrimination in increasing the vulnerability of children and youth affected by HIV/AIDS. *Report on participatory workshop run for Save the Children (UK). Unpublished.*

Convention on the Rights of the Child (1989), *G.A. res 44/25, annex, 44 UN GAOR suppl (No 49) at 167, UN Doc a/44/49.*

Culligan, K. (2001) *The AIDS orphans that slip through the Red Tape* The Sunday Times.

Defillipi, K. (2000) Integrated community home based care (ICHC). *AIDS 2000 Conference paper, Durban.*

Deininger, K., Garcia, M. & Subbarao, K (2003) AIDS-induced orphanhood as a systemic shock: Magnitude, impact and program interventions in Africa. *World Development* 31(7) 1201-1220.

Demographics for District 272 Available:

http://www.demarcation.org.za/demarcprocess/wards/xer3e/Cat_bdemogStats.asp
15 May 2002.

Department of Education, Health and Social Development (2000) *National integrated plan for children infected and affected by HIV/AIDS. Pretoria.*

Department of Health (2000) *HIV/AIDS & STD strategic plan for South Africa 2000-2005. Pretoria.*

Desmond, C. & Gow J. (2001). The current & future impact of HIV/AIDS on South Africa's children and the policy response. *AIDS, Public Policy & Child Well-being Chpt. 6.* Ed. Giovanni Andrea Cornia, UNICEF.

Donovan, C., Bailey, L., Mpyisi, e. & Weber, M. (2003) Prime age adult morbidity and mortality in rural Rwanda: Effects on household income, agricultural production and food security strategies. *Food security research project.* USAID, Kigali.

Drimie, S. (2002) *The impact of HIV/AIDS on rural households and land issues in Southern and Eastern Africa: A Background paper prepared for the Food and Agricultural Organisation.* Sub-regional Office for Southern and Eastern Africa.

Fassa, M. (2000) HIV/AIDS impact assessment on Central African Republic and Cote d'Ivoire educational system. *AIDS 2000 Conference paper, Durban.*

Fincham, R. & Thomas, G (1984) Nutritional intervention: A Ciskei and Eastern Cape Perspective. *Second Carnegie inquiry into poverty and development in South Africa.* Conference paper no. 213, University of Cape Town.

- Foster, G., Makufa, C., Drew, R. & Kralovec, E. (1997) Factors leading to the establishment of child-headed households: the case of Zimbabwe. *Health Transition Review*, 7 (Suppl 2) 155-68.
- Fox, S. (2001) *Investing in our future: Psychosocial support for children affected by HIV/AIDS*. UNAIDS Best Practise Collection.
- Fox, S. (2002) Hidden needs of children: Psychosocial support for children affected by HIV/AIDS. *AIDS 2002 Conference Paper, Barcelona*.
- Giese, S. (2002a) *The National Children's Forum on HIV/AIDS 22nd-24th August 2001*. Workshop Report. Children's Institute, University of Cape Town.
- Giese, S. (2002b) A summary of the issues raised at the National Children's Forum on HIV/AIDS 22nd-24th August 2001. *Presented at the conference "A call to co-ordinated action for children affected by HIV/AIDS"*. June 2002, Gauteng.
- Gilborn, L., Nyonyintono, R., Kambumbuli, R. & Jagwe-Wadda, G. (2001) *Making a difference for children affected by AIDS: Baseline findings for operation research in Uganda*. USAID, Washington, DC.
- Haddad, L. & Gillespie, (2001) *Effective food and nutrition policy responses to HIV/AIDS: What we know and what we need to know*. FCND Discussion Paper No. 112, IFPRI.
- Hunter, S. (1990) Orphans as a window on the AIDS epidemic in Sub-Saharan Africa. *Social science & medicine*. 31(6) 681-690.
- Hunter, S. & Williamson, J. (1998) *Children on the brink: Strategies to support children isolated by HIV/AIDS*. Arlington, VA: USAID.
- Hunter, S., Kaijage, F., Maarck, P., Kiondo, A. & Masanja, P. (1997) Using rapid research to develop a national strategy to assist families affected by AIDS in Tanzania. *Health transition review*, 7(Suppl) 393-419.
- Kahinga, V. (2000) Scouts youth and home based care. *AIDS 2000 Conference paper, Durban*.
- Kaseke, S. & Germann, S. (2002) Facilitate psychosocial support for children affected by AIDS through kids clubs. *AIDS 2002 Conference paper, Barcelona*.
- Kelesitse, N. (2000) AIDS, home based care and the status of women in Botswana: A case study of Mogoditshane. *AIDS 2000 Conference paper, Durban*.
- Kikule, E. (2003) A good death in Uganda: survey of needs of palliative care for terminally ill people in urban areas. *BMJ*. 327, 192-194.

- King, J., Whiteside, A., Crownie, D., Tomlinson, J. (2000) Assessing the impact of AIDS on the education sector: The case of Swaziland. *AIDS 2000 Conference paper, Durban.*
- Lee, T., (2002) Families, orphans and children under stress in Zimbabwe. *Evaluation and program planning* 25, 459-470.
- Lenya, C., Dimba, R., Aduwe, P. & Odiembo, L. (2002) Children as home carers for their "AIDS bed ridden" parents. *AIDS 2002 Conference paper, Barcelona.*
- Madhavan, S. (2003) Fosterage patterns in the age of AIDS: continuity and change. *Social science and medicine*. In press, Corrected Proof, Available on line 29 August 2003.
- Magada, L. (2002) Who cares for the carer *AIDS 2002 Conference paper, Barcelona.*
- Marcus, T (1999) *Wo! Zapela Izingane. Living and dying with AIDS*. Pietermaritzburg School of Human & Social Science, University of Natal.
- Masika, E. (2000) Home based care and gender study. *AIDS 2000 Conference paper, Durban.*
- Mehta, S., Sakhuja, A. & Panwar, M. (2002) Community based HIV/AIDS care support programme with child focus- A step towards ensuring a future: Experiences from a state-wide community based care and support programme in India. *AIDS 2002 Conference paper, Barcelona.*
- Naamatovu, S., (2000) Importance of counselling children/orphans. *AIDS 2000 Conference paper, Durban.*
- Nantenza, C., Sharpe, U., Ssentongo, R., Nabposa, G (2000) Culture and grieving children. *AIDS 2000 Conference paper, Durban.*
- National guidelines for social services to children infected and affected by HIV/AIDS. Dept of Social Development, Pretoria.
- Ntozi, J. (1997a) AIDS morbidity and the role of the family in patient care. *Health Transition Review*, 7 (Suppl) 1-22.
- Ntozi, J. (1997b) The effect of AIDS on children: the problem of orphans in Uganda *Health Transition Review*, 7 (Suppl) 23-40.
- Ntozi, J. & Nakayiwa, S. (1999) AIDS in Uganda: How has the household coped with the epidemic? *The continuing African HIV/AIDS epidemic*, 155-181. Canberra, Australia.

- Ntozi, J. & Zirimenya, S. (1999) Changes in household composition and family structure during the AIDS epidemic in Uganda *The continuing African HIV/AIDS epidemic*, 193-209. Australian National University, Canberra.
- Ntozi, J., Ahimbisibwe, F., Odwee, J., Aiyga, N. & Okurut, F. (1999) Orphan Care: the role of the extended family in northern Uganda. *The continuing African HIV/AIDS epidemic*, 225-236. Australian National University, Canberra.
- Nyamayarwo, A. (2000) The dilemma of HIV positive parents reviewing serostatus to their children. *AIDS 2000 Conference paper, Durban*.
- Nyambedha, E., Wandibba, S. & Aagaard-Hansen, J. (2003) Changing patterns of orphan care due to the HIV epidemic in western Kenya, *Social science & medicine*. 57 (2003) 301-311.
- Opundo, L. (2000) Promoting home based care & support for infected and affected by HIV/AIDS in Kayole slums, Nairobi. *AIDS 2000 Conference paper, Durban*.
- Piwoz, E. & Preble, E. (2000) *HIV/AIDS and nutrition: A review of the literature and recommendations for nutritional care and support in Sub-Saharan Africa*. USAID, Washington.
- Prang, C. (2000) Participatory tolls for appraising the needs of children affected by AIDS in Cambodia. *AIDS 2000 Conference paper, Durban*.
- PSLSD (1994) *Project for statistics on living standards and development: South Africans rich and poor: Baseline household statistics*. South African Labour and Development Research Unit, University of Cape Town.
- Ramphela, M. (1993) *A bed called home*. Cape Town: David Philip.
- Russel, M. & Schneider, H. (2000) *A rapid appraisal of community-based HIV/AIDS care and support programs in South Africa*. Johannesburg: Centre for Health Policy, University of Witswatersrand.
- Schroeder, E. (2003) The impact of HIV/AIDS on food security- a study of orphan adoption in rural Ingwavuma, KwaZulu-Natal. Unpublished dissertation, Pietermaritzburg.
- Sengendo, J. & Nambi, J. (1997) The psychological effect of orphanhood: a study of Rakai district. *Health transition review*, 7 (Suppl) 105-124.
- Sentumbwe, S. & Nantege, N. (2000) A comparative study of home and hospital based AIDS care in Uganda. *AIDS 2000 Conference paper, Durban*.
- Smart, R. (1999) *Children living with HIV/AIDS in South Africa: A rapid appraisal*. Report written for the Interim National HIV/AIDS Care and Support Task Team.

- Sok, P. (2000) Basic demographics of HIV+ patients at Sihanouk hospital centre of HOPE, Phnom Penh, Cambodia. *AIDS 2000 Conference paper, Durban.*
- South African Schools Act 84 (1996).
- Thompson, S. (2001, 25 June) *AIDS orphans in dire need.* The Citizen.
- Tlou, S. (2000) The girl child and AIDS: the impact of secondary caregiving in rural girls in Botswana. *AIDS 2000 Conference paper, Durban.*
- UNAIDS (2000) *AIDS: palliative care.* Best practise collection. Geneva, UNAIDS.
- UNAIDS (2001) *Reaching out, scaling up: Eight studies of home and community care for and by people with HIV/AIDS.* Geneva, UNAIDS.
- UNDP (2002) *Conceptual shifts for sound planning. Towards an integrated approach to HIV/AIDS and poverty.* Concept paper. Regional project on HIV and Development. UNDP.
- UNICEF (1999). *Children orphaned by AIDS; Front line responses from eastern and southern Africa.* UNICEF.
- USAID, UNAIDS & UNICEF (2002). *Children on the brink 2002: A joint report on orphan estimates and program strategies.* USAID. Washington, DC.
- Van der Waal, C. (1996) Rural children and residential instability in the Northern Province of South Africa. *Social Dynamics*, 22(1) 31-54.
- Walker, L. (2002) *We will bury ourselves- A study of child-headed households on commercial farms in Zimbabwe.* Farm Orphan Support Trust, Harare.
- Wekesa, E. (2000a) Challenges in managing the impact of HIV/AIDS on child survival and development in Kenya. *AIDS 2000 Conference paper, Durban.*
- Wekesa, E. (2000b) The impact of HIV/AIDS on child survival and development in Kenya. *South Africa: AIDS Analysis Africa*. 10(4) 12-14.



Ingwavuma Orphan Care

HOUSEHOLD SURVEY ON CHILDREN CARING FOR ILL PARENTS

OCT - DEC 2001

APPENDIX - Questionnaire

HOUSEHOLD ID NUMBER

--	--	--

Address of visiting point:

Name of head of household:

Date of consent:

Date of interview:

/	/	2001
/	/	2001

Start time:

End time:

Food parcel received

INTRODUCTION:

Hello, my name is _____

I am collecting information that will be used by Ingwavuma Orphan Care to improve services for households with children caring for their sick parents.

I would like to ask you if you would be prepared for your children to be interviewed about your situation and the help that your household receives in dealing with your illness

Do you agree to this request?

Yes	No
-----	----

→ close interview

Sign consent box. Thank you very much again for agreeing to participate in this research. Before we start, I would like to remind you that the answers you give will be put together with lots of other interviews that are being conducted around Ingwavuma. Your name will be confidential and this household will not be identified in any of the reports or to anyone in this community. I am saying this because it is important that you can feel free to speak openly and honestly about your experiences. There are no right and wrong answers. I have a questionnaire here, which lists all the questions I am going to ask. If you do not understand any of the questions, please tell me and I will explain. You do not have to answer a particular question if you do not want to. You are also free to stop the interview at any time if you do not want to continue.

Do you have any questions before we start?

Any other questions (not about the research process) say: We will cover many issues in this interview. Can I make a note of this/these question(s) so that we can discuss it at the end?

SECTION 1 : HOUSEHOLD PHYSICAL CHARACTERISTICS

In the interview we will be talking about this household.

By "household" I mean all the household members on this property who live and eat together, and who sleep here at least 2 nights a week.

1.1 Interviewer: Indicate the type of MAIN DWELLING that the household occupies

1	House / brick structure on own land	3	Traditional dwelling on other person's property
2	Traditional dwelling / hut / structure made of traditional materials on own land	4	Informal dwelling / shack

1.2 How long does it take to walk to the nearest water source? min

1.3 What type of toilet facility is usually used by this household? READ OUT

1	Flush toilet	3	Pit latrine with ventilation (VIP)	5	Bucket toilet
2	Chemical toilet	4	Other pit latrine	6	None / open veld

1.4 Can you get to any of the following public transport services within 15-minutes (1km) of this house if you are WALKING?

READ OUT and answer one at a time:

(a)	Bus	yes	no	D/K
(b)	Minibus taxi	yes	no	D/K

1.5 Can you get to any of the following facilities within a 30-minutes (2km) of this house if you are WALKING?

READ OUT and answer one at a time:

(a)	Primary school	yes	no	D/K
(b)	Secondary school	yes	no	D/K
(c)	Clinic / hospital	yes	no	D/K
(d)	Shop where basic foodstuffs can be bought (eg, bread, milk)	yes	no	D/K

SECTION 2: HOUSEHOLD DEMOGRAPHICS

READ OUT

Now I would like to ask you about all the members of this household. By "household" I mean all those who live on this property, eat together and sleep here at least 2 nights a week - including all babies and non-family members who are regarded as part of the household.

Who is the head of this household? (By "head" I mean the person who is in charge of the household on a day-to-day basis.)
(Write name in Column 1.)

Now please tell me the first names of all the other members of this household. (Write in names.)

Were there any members of this household who passed away in the last three years? Please tell me their names too.

2.2 Interviewer: identify the following individuals (each member should be classified once only)

- (a) Circle members who died in the last 3 years
- (b) Which household members are healthy?
- (c) Which members have been ill for more than a month?

2.3 Is / was ... male or female?

2.4 How old is / was ... (age in completed years)

Give age in figures only; less than one 1 year = 0

2.5 Which best describes ...'s occupation? (If deceased, ask for occupation before member became too sick)

(READ OUT)

- 1 pre-school / not yet in school
- 2 studying / at school
- 3 of school age (7-18 yrs), but not attending school
- 4 employed (working full-time or part-time)
- 5 unemployed - looking for work
- 6 stay at home by choice / housewife
- 7 retired / pensioner
- 8 disabled / too ill to work
- 9 other (specify)

(name)	(name)	(name)	(name)	(name)	(name)	(name)	(name)	(name)	(name)	(name)	(name)
1	2	3	4	5	6	7	8	9	10		
1	2	3	4	5	6	7	8	9	10		
1	2	3	4	5	6	7	8	9	10		
M	F	M	F	M	F	M	F	M	F	M	F
1	1	1	1	1	1	1	1	1	1	1	1
2	2	2	2	2	2	2	2	2	2	2	2
3	3	3	3	3	3	3	3	3	3	3	3
4	4	4	4	4	4	4	4	4	4	4	4
5	5	5	5	5	5	5	5	5	5	5	5
6	6	6	6	6	6	6	6	6	6	6	6
7	7	7	7	7	7	7	7	7	7	7	7
8	8	8	8	8	8	8	8	8	8	8	8
10	10	10	10	10	10	10	10	10	10	10	10

Interviewer: write in names at the top of each column

	(name)	(name)	(name)	(name)	(name)	(name)	(name)	(name)	(name)	(name)	(name)
2.6	What is / was ...'s relationship to the head of the household (i.e. to the person in column 1)?										
	1 husband / wife / partner	1	1	1	1	1	1	1	1	1	1
	2 son / daughter / stepchild	2	2	2	2	2	2	2	2	2	2
	3 adopted child / foster child	3	3	3	3	3	3	3	3	3	3
	4 brother / sister	4	4	4	4	4	4	4	4	4	4
	5 father / mother	5	5	5	5	5	5	5	5	5	5
	6 grandparent / great grandparent	6	6	6	6	6	6	6	6	6	6
	7 grandchild / great grandchild	7	7	7	7	7	7	7	7	7	7
	8 other relative (eg in-laws or aunt / uncle)	8	8	8	8	8	8	8	8	8	8
	9 non-related person	9	9	9	9	9	9	9	9	9	9

ask for members of school age but not attending.

2.7 What are the reasons for this child not attending school?

ID #	Name	REASON

2.8 Are there any children under the age of 18 who have left this household and are now living elsewhere?

Yes No → skip to Section 5

2.9 Did any of these children leave the household for reasons related to illness or death in the household (eg. lack of money / food / adults to provide care / etc.)

Yes No → skip to Section 5

2.10 Please tell me the names of the children who left due to illness / death (Record name, ensuring that child is not already listed on household roster)

(name)	(name)	(name)	(name)	(name)	(name)	(name)
M	F	M	F	M	F	M

2.11 Is ... male or female?

2.12 How old is ... (age in completed years)

Give age in figures only, less than one 1 year = 0

Now I would like to talk about the health issues that this household has been dealing with. I would like to talk particularly about ... (name of sick parent).

3.1 Ask main carer For how long has ... not been herself or been unable to carry on as s/he used to?

(months)	(days)

3.2 Ask: Please tell me if the ill person can do the following activities independently, or if s/he needs help. [READ OUT]

(a) Eating	1	independent	2	needs help
(b) Moving in and out of bed	1	independent	2	needs help
(c) Personal care (shave, clean teeth)	1	independent	2	needs help
(d) Getting on and off the toilet	1	independent	2	needs help
(e) Washing him/herself	1	independent	2	needs help

(f) Walking on a level surface	1	independent	2	needs help
(g) Walking on stairs or uneven surfaces	1	independent	2	needs help
(h) Dressing	1	independent	2	needs help
(i) Controlling bowels	1	can control	2	can't control
(j) Controlling bladder	1	can control	2	can't control

3.3 Ask: Does ... have any of the following problems? [READ OUT]

- 1 chronic diarrhoea (lasting more than one month)?
- 2 chronic cough (lasting more than one month)?
- 3 weight loss?
- 4 weakness?
- 6 difficulty breathing?

Yes	No	D/K
Yes	No	D/K
Yes	No	D/K
Yes	No	D/K
Yes	No	D/K

- 5 pain?
- 7 confusion?
- 8 any other symptoms?

Yes	No	D/K
Yes	No	D/K
Yes	No	D/K

↓
specify: _____

3.4 Which of these problems that you have mentioned causes / caused the most difficulties for this household? (list symptom # from 5.3 above)

3.5 Why do you say that? (probe fully for IMPACT / effect on the household)

Symptom # REASON

SECTION 4: CHILD CARERS

Speak to the children of the household:

4.1 Which person in the household is the main caregiver who looks after... (the sick person)?

Name & Age:

(eg. Helps them to wash, dress, eat, take medication etc.)

4.2 How many other children in the household help to care for... (the sick person)?

number of children (under 18):

4.3 What type of regular activity did you do before your parent became sick, that you don't do now?

- | | |
|---|------------------------------|
| 1 | income generating activities |
| 2 | School/studies |
| 3 | Playing with friends/sport |

- | | |
|---|--|
| 4 | Housework/gardening |
| 5 | Other regular activity (specify) _____ |

4.4 Have you, the children tried to find other ways to make money?

Yes

No

D/K

if yes: how? (specify) _____

4.5 If your sick parent has the following symptoms, what do you do?

a) Pain	
b) Mouth sores	
c) Fever	
d) Diarrhoea	

4.6 Do you have any pills for your parent in the house? (Write down the names if known) Do you know what they are for?

Name of pill	What for:

4.7 Do you think that your parent will get better?

Yes	No	D/K
-----	----	-----

4.8 Do you ever worry about anything?

Yes	No	D/K
-----	----	-----

if yes: what? (specify)

- | | |
|---|------------------------|
| 1 | Not having enough food |
| 2 | Caring for the parent |
| 3 | Parent dying |
| 4 | Younger siblings |
| 5 | The future |
| 6 | Other _____ |

4.9 What is the biggest hardship for you at present?

4.10 What help do you most need?

- | | |
|---|-----------------------------|
| 1 | Help with caring for parent |
| 2 | Material support |
| 3 | School support |
| 4 | Social/emotional support |
| 5 | Other _____ |

4.11 How do you feel about the future?

- | | |
|---|----------------|
| 1 | Helpless |
| 2 | In God's hands |
| 3 | Positive |
| 4 | Other _____ |

5.1 I would like to find out more about the type of care or support this household has received from the community:

- A Thinking about the community around you, who is aware that there has been chronic illness / death in this household? *[complete column A below]*
- B Of these, which people / groups have been particularly supportive to the sick person(s)? *[complete column B below]*
- C Which people / groups have been particularly supportive to the household? *[complete column C below]*
- D Please describe the type of care or support received from these people / groups (what exactly did they do?) *[complete column D below]*

Read out:

- 1 Have **neighbours** been aware of illness / death?
- 2 Have **friends / social groups** been aware...?
- 3 Have **schools** been aware...?
- 4 Have **church groups** been aware...?
- 5 Have **other local organisations** been aware...?
- 6 Have the **extended family elsewhere** been aware...?
- 7 **Who else** has been aware?

		A (aware)			B (support sick)			C (support HH)			D Type of care or support received
1	Have neighbours been aware of illness / death?	Yes	No	D/K	Yes	No	N/A	Yes	No	N/A	
2	Have friends / social groups been aware...?	Yes	No	D/K	Yes	No	N/A	Yes	No	N/A	
3	Have schools been aware...?	Yes	No	D/K	Yes	No	N/A	Yes	No	N/A	
4	Have church groups been aware...?	Yes	No	D/K	Yes	No	N/A	Yes	No	N/A	
5	Have other local organisations been aware...?	Yes	No	D/K	Yes	No	N/A	Yes	No	N/A	
6	Have the extended family elsewhere been aware...?	Yes	No	D/K	Yes	No	N/A	Yes	No	N/A	
7	Who else has been aware?				Yes	No	N/A	Yes	No	N/A	

5.2 How often do family members visit?

1	Every day	4	A few times a month	7	Never
2	Most days	5	Once a month		
3	Once a week	6	Less than once a month		

5.3 Which relatives visit most often? (List up to 3)

relationship to child carers:

1	Gogo	5	Mkhulu	9	Other female
2	Auntie	6	Uncle	10	Other male
3	Mamancane/nkhulu	7	Babamkhulu/-mncane		
4	Older sister	8	Older brother		

5.4 Are your relatives happy to help your family?

Yes	No	D/k
-----	----	-----

5.4a Why do you say that? _____

5.5 Do you think children in this household have been treated badly or differently from other children because of this illness / death?

Yes	No	D/K
-----	----	-----

5.6 *if yes. Which people treat these children differently or badly? [DO NOT PROMPT]*

1	other children
2	teachers
3	the community / neighbours

4	foster parents / guardians
5	foster brothers / sisters
6	other relatives (specify): _____
7	other non-relatives (specify): _____

5.7 Can you give me some examples of how they are / were treated differently or badly? _____

SECTION 6 : CONCLUSION

6.1 Are there any additional issues you would like to raise in connection with the impact of illness on this household?

6.2 Is there anything we talked about that was particularly upsetting for you to discuss?