

IMPACT OF AIDS ON OLDER PEOPLE IN AFRICA

Zimbabwe Case Study



WORLD HEALTH ORGANIZATION
NONCOMMUNICABLE DISEASES AND MENTAL HEALTH
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AGEING AND LIFE COURSE (ALC)

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List of acronyms

AIDS	acquired immunodeficiency syndrome	NPH	Noncommunicable Disease Prevention and Health Promotion
ALC	Ageing and Life Course	NGO	nongovernmental organization
ARCs	AIDS-related conditions	OPD	outpatients department
ARI	upper respiratory-tract infections	PHC	primary health care
CDCs	cardiovascular diseases	PTB	pulmonary tuberculosis
CDC	Centre for Disease Control	PWA	person with AIDS
CSO	Central Statistical Office	SDA	Seventh-Day Adventist Church
ESAP	Economic Structural Adjustment Programme	SDF	Social Dimensions Fund
FACT	Family AIDS Counselling Trust	SPSS	Scientific Package for Social Scientists
GDP	gross domestic product	SSCF	Small Scale Commercial Farming Sector
GoZ	government of Zimbabwe	SSW	School of Social Work
HIV	human immunodeficiency virus	STI	sexually transmitted infections
ICDS	intercensal demographic survey	UN	United Nations
IDS	Institute of Development Studies	UNAIDS	United Nations AIDS Programme
LSCF	Large Scale Commercial Farming Sector	UNDESA	United Nations Department of Economic and Social Affairs
MDS	Minimum Data Set	UNICEF	United Nations Children Fund
MoHCW	Ministry of Health and Child Welfare	UZ	University of Zimbabwe
MNCs	multinational companies	VHW	village health worker
MPSLSW	Ministry of Public Service, Labour and social Welfare	WHO	World Health Organization
NACP	National AIDS Coordination Programme	ZIMPREST	Zimbabwe Programme for Economic and Social Transformation
NHP	National Health Profile	ZNFPC	Zimbabwe National Family Planning Council
NIA	National Institute on Aging		

*Looking after orphans is like starting life all over again,
because I have to work on the farm, clean the house, feed the children,
and buy school uniforms. I thought I would no longer do these things again.*

I am not sure if I have the energy to cope.

**A 65-year-old man, Makoni, Manicaland,
the main care-giver of three school-aged children**

Executive summary

The project “Impact of AIDS on older people in Africa”, was designed to develop a methodology to examine the impact of HIV/AIDS on older caregivers preliminary in four countries in Africa, **Zimbabwe, Ghana, South Africa** and **Tanzania**. Starting with a pilot project in Zimbabwe, a mix of qualitative and quantitative research methods was designed, tested and applied to provide statistical and qualitative information on the role of older people in HIV/AIDS-related care, and on the burden they bear. This pilot study was carried out in six provinces selected to represent the diversity of the Zimbabwean population.

Working in close collaboration with governmental departments, non-governmental organizations (NGOs), and academic institutions, the WHO Ageing and Life Course team (ALC) aimed to provide baseline data which would facilitate efforts to improve institutional and community understanding of the plight of older people in the context of the AIDS epidemic in Africa. It is expected that the data will be useful for policy and programme initiatives that can potentially strengthen the capacity of older people to act as care providers to their HIV/AIDS-affected families.

This report of the Zimbabwean pilot study is presented in four sections. Section one provides background information to the study, sets out its objectives and describes its methodology (sampling and definition of subjects; site selection; data collection; brief discussion on the study’s strengths and limitations).

Section two presents the composition and characteristics of the sample, such as (living arrangements, religion, occupation and sources of income) and provides an analyses and discussion of the key findings of the study to include (the main roles of

those caring for persons with HIV/AIDS: providing food, medical care, psychological support and daily physical care).

The findings indicate that barriers to care for person(s) with AIDS (PWA) and orphans include: financial constraints; lack of basic necessities such as food; burn-out; stigma; violence; fear of contracting the disease and; frustrations inherent in performing daily chores (e.g. cleansing, feeding and washing). As the findings indicate, older caregivers are under serious financial, physical and emotional stress due to their care-giving responsibilities. The study also documented a high prevalence of abuse related to care-giving – in particular verbal abuse; accusations of witchcraft (sometimes leading to physical violence) as well as stigma. Older people stated that their motivation for providing care to people with HIV/AIDS and orphans was a demonstration of love and a desire to make those ill and the children left behind as comfortable as possible. They also indicated that they were caring for orphans either simply because they were the only people in the family who could take on the responsibility or because the patient had asked them before they died to take care of the soon-to-be orphans.

Section three of the report suggests strategies and recommendations for a concerted effort by the government, NGOs, community based groups and organisations to strengthen the capacity of the older persons to perform their duties.

The fourth section summarises the key points of the pilot study and points the way forward.

Additional information is presented in the appendices on background to Zimbabwe, national health profile, situation of older people, profiles of the study sites and the study questionnaire.



Background, problem identification and study methodology

1.1 Introduction

According to the World Health Organization (WHO) and the United Nations AIDS Programme (UNAIDS) 40 million people were living with HIV/AIDS as of the end of 2001 and AIDS had resulted in more than 20 million deaths since the first clinical evidence was reported in 1981 (UNAIDS, 2002).

UN data further reveal that although sub-Saharan Africa makes up only 10% of the world's population, 84% of the estimated cumulative adult and child HIV/AIDS-related deaths had occurred in the region and seven out of every ten new HIV infections occur in this region. Projections indicate that by 2004, an additional 14 million HIV-infected people in sub-Saharan Africa will develop full-blown AIDS, making it by far the largest disease burden of all world regions (US Bureau of the Census, 1999).

It is indisputable that the high incidence of HIV/AIDS in the sub-Saharan African region is leading to a devastation of individual and family life. Recent studies in Eastern (Williams A, Tumwekwase, G. 1998) and Southern Africa (UNICEF, 1999) indicate that women and children are AIDS' greatest victims. Zimbabwe is one of the countries hardest hit by the pandemic in sub-Saharan Africa, with an estimated 33.7% (2 million) of the adult population living with AIDS as of end 2001. (UNAIDS, 2002).

Throughout sub-Saharan Africa, by necessity or voluntary contribution, older people – particularly older women – are key resources for combating AIDS and alleviating its impact. At the household level, they are the persons who provide daily care for both AIDS patients and children left orphaned by the pandemic. These older people have taken on new roles by providing care and financial support to orphaned children, playing child-rearing roles

within their extended families and continuing their more traditional roles as advisors to their adult children and grandchildren. They largely absorb the enormous additional burdens placed on families and societies by the AIDS pandemic.

1.2 Rationale for study

In contrast with the available knowledge about the impact of AIDS on children in sub-Saharan Africa (UNICEF, 1998), little is known about the impact of AIDS on older people in Africa, their health needs, their role in care and the response of health systems to their current situation. This study sought to enhance knowledge about the complexities of AIDS and ageing in Africa. The results obtained from the study, it is hoped, might provide much needed evidence to facilitate dialogue and advocacy efforts aimed at improving health systems' capacity to respond to the problem. In particular, the results are expected to help promote and strengthen a sustainable primary health care response to the health needs of affected older people.

The study was therefore designed to develop, test and validate a research methodology based on complementary approaches (qualitative and quantitative) to assess the impact of AIDS on older people in Zimbabwe, in particular, and in Africa, in general. The validation of the methodology through this pilot study could prompt the launch of a multi-country study in other sub-Saharan African countries. This would generate the much-needed data on which to base interventions to effectively support older people faced with the consequences of the HIV/AIDS pandemic in Africa.

1.3 Specific objectives

- To develop, test and validate a methodology to

examine the impact of HIV/AIDS on older care-givers

- To identify barriers to supporting older people in the context of HIV/AIDS
- To create a body of evidence on the needs and contributions of older people dealing with the HIV/AIDS pandemic
- To develop policy and programme interventions with the government, NGOs and academia for supporting older persons as care-givers and surrogate parents for orphaned children
- To initiate capacity-enhancing programmes with health and social welfare services, especially primary health-care providers and home-based care-givers, and to respond to the impact of the pandemic on older carers
- To explore the feasibility of establishing a multi-centric study based on the research methodology developed for this pilot project in other sub-Saharan Africa countries.

While the preliminary stage of the project was directly designed with the purpose of piloting the methodology, it was hoped from the beginning that the intervention-oriented surveys conducted in various parts of Zimbabwe would prompt immediate action at the community level.

1.4 Study methodology

The project's concept was developed by WHO to address the paucity of data on the role of older people in the context of the AIDS pandemic in Africa and the burden sustained by them as a consequence. With initial support from UNAIDS, and later the U.S National Institute on Aging (NIA), the main focus was to test and validate a methodology that might provide essential information for policy development.

The project was initially envisaged to employ a solely participatory/qualitative approach, which promotes consultation and use of multi-sectoral approaches to problem identification, analysis and action (Chambers, 1997; Agyarko, 1997). This was subsequently expanded to include quantitative data, largely as a recognition of the paucity of information (both qualitative and quantitative) on the role

TABLE 1. QUANTITATIVE AND QUALITATIVE METHODS

Methodology/ Characteristics	Strengths	Weaknesses
Quantitative	Makes aggregation possible Provides results whose reliability is measurable Allows simulation of different policy options	Sampling and non-sampling errors Misses what is not easily quantifiable Fails to capture intra-household issues
Qualitative	Richer definition of problem More insight into causal processes More accuracy and depth of information on certain questions	Lack of generalisability Difficulties in verifying information

Source: Adapted from, Carvalho and White (1997)

of older people in HIV/AIDS related care. In addition, by incorporating both types of data, the project would directly contribute to the WHO-led project *Creating a Research Directory, Minimum Data Set and Survey on Ageing in Countries of the African Region (MDS)*. It was therefore envisaged that data from the AIDS research would feed information into the MDS to further inform policy and project initiatives.

While acknowledging the strengths and weaknesses of each approach, there were further reasons for choosing mixed-methods of qualitative and quantitative techniques for this pilot study. They were chosen to benefit from the strengths of each other and to minimise the weaknesses inherent in applying them individually, as summarised in Table 1.

Drawing on experiences in the field of poverty studies, Carvalho and White (1997) have argued that the quantitative approach to problem measurement and analysis typically uses random sample surveys and structured interviews for data collection (mainly, quantifiable data) and analyses it using statistical techniques. By contrast, the qualitative approach typically uses purposive sampling and semi-structured or interactive interviews to collect data- mainly data relating to people's judgements, attitudes, preferences, priorities, and/or perceptions about a subject- and analyses it through sociological or anthropological research techniques.

In general terms, quantitative approaches are renowned for having breadth, and qualitative approaches for having depth. The key is to combine the breath of one and the depth of another to gain from the strength of the synergy they create and to minimise their weaknesses through;

- Integrating the quantitative and qualitative data methodologies
- Examining, explaining, confirming, refuting, and/or enriching information from one approach with that from the other; and
- Merging the findings from the two approaches into one set of policy recommendations (Carvalho and White, 1997) .

With this focus, the research protocol was designed in consultation with stakeholders, NGOs and service providers at the local level. This process made it possible to solicit ideas for the development of the project concept. In February 2000, a key stakeholder's meeting was held in Zimbabwe, which brought together eighteen people. The stakeholders were drawn from WHO Headquarters; WHO African Regional Office (AFRO); the WHO Zimbabwe country office; UNAIDS Office in Zimbabwe; Zimbabwe's National AIDS Coordination Programme; government ministries (the Ministry of Health and Children's Affairs (MoHCW) and Ministry of Public Service; Labour and Social Welfare (MPSLSW); the School of Social Work and the Institute of Development Studies of the University of Zimbabwe and civil society organizations such as HelpAge International; HelpAge Zimbabwe and Oak Foundation. They deliberated on the draft research protocol, made suggestions on the areas of investigation and set up a research supervisory board. The stakeholders confirmed the lack of data on older people affected by AIDS, particularly in Africa and suggested the broad areas for investigation as well as a recommendation for the use of secondary data and the development of a questionnaire to generate primary data. It was thus decided that the pilot study should be focused on:

- Levels of morbidity
- Numbers of older persons providing care for adult children with AIDS-related ailments as well as children affected by AIDS (loss of one or both parents)
- Number of care recipients per care-giver
- Household income distribution of expenditures including medical and funereal costs, and those related to caring for children orphaned by AIDS
- Access and utilization of health and other social services, knowledge of preventive care-giving practices

- Self-reported grief and ailments resulting from care-giving roles and loss of property, stigma, abuse, dissolution of household.

Research coordinators, team leaders and research assistants were identified by the group of stakeholders. The research team comprised the following:

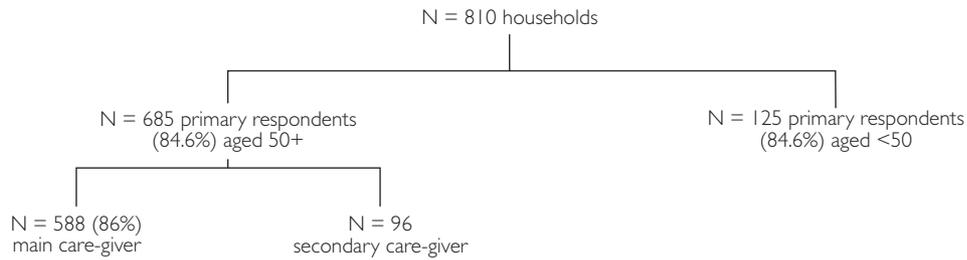
- a. One technical officer from the WHO Headquarters (Geneva) as the principal investigator
- b. Two principal researchers (coordinators), both academics at the Institute of Development Studies (IDS) and the School of Social Work (SSW), University of Zimbabwe, respectively
- c. Three team leaders from Zimbabwe's Central Statistics Office (CSO), MoHCW, and School of Social Work – University of Zimbabwe, respectively
- d. Sixteen research assistants consisting of social science undergraduate and postgraduate students of the University of Zimbabwe as well as health care providers.

Three teams carried out the fieldwork, each team comprising of a coordinator, a team leader and several research assistants.

1.5 Sampling and definition of subjects

The sample selection was pre-determined and purposive; i.e., the purposive sampling method is based on some pre-determined characteristic where the researcher selects the sample subjectively based on this characteristic (Patton, 1990). However, the sample selection aimed to ensure that the spectrum of respondents was as representative of the Zimbabwean population as possible. Given the sensitivity surrounding HIV/AIDS and the stigma suffered by those who admit of their infection, it is not easy to have an open sampling process. This was overcome by using a snowball method to identify participants. For example, in every community participants were first identified by community health workers, nurses, and volunteer HIV/AIDS care providers, who knew of households with an older person caring for a terminally ill person with HIV/AIDS. The identified individuals thus consented to participate in the study and were then asked if they were aware of other older people in their neighbourhood who were providing the same type of care or had provided such care in the immediate past. The research team could then

Figure 1. Study sample of households



go to these households and seek the permission from the head of the household, main care-giver or both to conduct an interview. In most cases the head of household was the main caregiver (mostly female). In other cases the head of household was the male spouse and permission would be asked to interview his spouse. There were a few instances where the male head of household co-participated in responding to the questions with his spouse, or answered on behalf of his spouse.

The calculation of the sample size was based on Zimbabwe's census protocol with modifications to accommodate for a higher urban distribution than that of the national rural/urban divide. Therefore this study had 40.3% urban and 59.7% rural while the national ratios are 32% urban and 68 % rural. This higher urban sample was decided on to cap-

ture different scenarios: i.e., in addition to Harare and Bulawayo (the major urban centres in Zimbabwe) to add a mining town and peri-urban areas.

Thus, the 276 urban respondents included those from (a) mining town, peri-urban and urban areas, while the 409 rural older persons resided in communal lands, squatter settlements, and commercial farm and resettlement schemes.

As illustrated in Figure 1, through the snowball sampling technique used to locate respondents, the total sample for the study from the six provinces corresponded to 810 respondents. However, some of these respondents were in their forties. Given that the study had aimed to focus mainly on the impact of the AIDS pandemic on older persons, the analysis of findings has been restricted to those respondents who were aged 50 years and above. The rationale behind this is explained in the Box 1.

Therefore the term "older people," in this report refers specifically to the 685 "older persons" aged 50 years and above who were a) caring for a terminally ill person with an AIDS condition (own child, grandchild, spouse or external family member) b) had cared for such a person(s) in the past, who had since died, and c) had not cared for a terminally ill person but are taking care of a child or children orphaned by AIDS d) were not the main care-givers for the above **but** were the head of household and, as such, a heavy burden would inevitably fall on them. Table 2 shows the provincial distribution of the group analysed in this report.

Most, if not all, the ethnic groups were represented in the six provinces and careful consideration was made to reflect the national ethnic proportions in the sample size calculation. As a result, the Zezuru ethnic group accounted for 26.9% of the total sample, the Ndebele/Kalanga constituted 23.1%, while the Manyika/Ndau constituted 22.5% of the sample. The Karanga accounted for 6.7% of the total sample with the remaining 4.4% being Shangani, Venda, Korekore or Sotho. The further

BOX 1. DEFINITION OF OLDER PERSON

The analysis in this report focuses on the 50-years-and-above age group as the primary data source. This benchmark age was chosen following extensive debate on what ought to be the appropriate cut-off point for an "older person" vis-à-vis discussion on chronological, cultural and functional categorization of people as "old." The researchers were aware that this was in tandem with discussions in gerontological circles to adopt 50 years as the age at which one is commonly categorized as "ageing", especially in Africa.

The debate was necessitated firstly by the fact that in most of the poor economies, the burden for survival puts people at a greater disadvantage than in rich countries, making them to age prematurely. Secondly, in most African traditions the title "older person" is socially dictated by one's role in society: for example becoming a grandparent confers such a title and the added respectability, regardless of the chronological age. The choice of 50 years was therefore agreed on in order to accommodate these definitional complexities and provides a sample base, which sociologically and chronologically merits the label "older person."

TABLE 2. PROVINCIAL DISTRIBUTION OF RESPONDENTS

Province	Harare	Bulawayo	Midlands	Manicaland East	Mashonaland South	Matabeleland	Total
Total	113	67	83	160	142	120	685
%	16.5	9.8	12.1	23.4	20.7	17.5	100

16.5% of the sample were citizens from countries neighbouring Zimbabwe mainly Mozambique, Malawi and Zambia; these people were located mainly in the mining towns.

The criteria for site selection were developed with the Zimbabwean Central Statistics Office (CSO) based on:

- I. Prevalence of HIV/AIDS
- II. Social class distribution
- III. Cultural/ethnic differences and groupings
- IV. Rural/urban differences
- V. Land use pattern (commercial farm, areas etc.)
- VI. Accessibility.

1.6 Data collection and ethical consent

Data were collected over a period of two weeks and interviews were conducted in the homes of caregivers and expanded by a few focus group discussions of older people.

Permission to conduct the study was obtained through a request made to the Medical Research Council (MRC) by the WHO Zimbabwe Country Representative. Once approved by the MRC, the Ministry of Health and Child Welfare informed the MoHCW heads in the study sites. These provincial and or district heads received the research teams, and introduced them to the community through community health workers, volunteer home-based care-givers and community leaders. Therefore the research was conducted following the nationally adopted ethical principles. Throughout its implementation the research team worked in close collaboration with MoHCW, with the full support of the Medical Research Council.

A visit was made to Lower Gweru to conduct a preliminary assessment of the situation on the ground. This visit was significant in that it helped the research team to improve upon the draft research instruments and also to identify potential strategies for locating likely respondents.

The core team of researchers developed a questionnaire and an interview guide for key informants.

Following a day's training on how to administer the questionnaire, and familiarization with it, a pre-test of the questionnaire was conducted in the Goromonzi area in Mashonaland East Province. The questionnaires were subsequently revised.

The revised questionnaires contained both qualitative and quantitative questions. The pre-test in Gweru made it clear that administering a quantitative questionnaire (close-ended) followed by an open-ended qualitative instrument, or vice versa, was time consuming and repetitive. As a result of the pre-testing of the questionnaire and interview guide, a combined questionnaire (qualitative and quantitative) was developed (appendix 5).

The 10-day fieldwork was conducted in January and February 2001. Three teams covered two provinces each as follows:

Team A: Matabeleland South Province and Bulawayo; areas covered; Gwanda district and Mzilikazi in Bulawayo,

Team B: Midlands and Manicaland Provinces; areas covered: Zvishavane and Makoni districts,

Figure 2. Map of Zimbabwe showing study areas**



* For details on study sites see appendix 4

** The pre-test site, Gweru is shown with an arrow. The study sites, which are indicated by stars are shown in close proximity to nearest big settlement areas.

Team C: Mashonaland East Province and Harare.

In the Harare area, the sites sampled for the study were Mbare, Highfield, Epworth and Hatfield. In Mashonaland East, Seke district was selected, and within this district eight out of 21 wards were included.

Permission was sought from respondents to interview them in their homes and, in all circumstances, a representative (mostly a volunteer home-based care provider or community nurse) accompanied the team during household visits.

Both qualitative and quantitative methods of data analysis were employed in the study. The analysis of the qualitative information was done through team debriefing during data collection. The teams had daily debriefing on the key issues from the interviews and a research assistant compiled notes. At the end of the visit to a community when the team concluded data collection – some time was set aside to discuss and document the key qualitative findings pertaining to the site, and the daily notes are used as a basis for discussion. Finally, at the end of the fieldwork, all three-research teams came together for a one-day debriefing in Harare. At this meeting, the 18 research assistants and the team leaders identified issues of commonality and difference.

The qualitative responses were sifted out of the questionnaires, the open-ended responses having been recorded with special emphasis on capturing quotations verbatim and in local languages. The research teams had been encouraged to write out proverbs and quotations in the local language if translation was a problem. The responses formed the first level of analysis. To avoid duplications, the people recording the responses used their discretion and did not repeat issues that had already been raised. In this report only quotations of people aged 50 years and above have been used in conformity to the quantitative analysis age cut off.

The next level involved integrating these quotations and responses into key issues discussed and recorded during the team meetings and the feedback session. The responses were divided into sections as individual qualitative reports. This was later incorporated in the quantitative analysis, which had been extracted from the questionnaire and analysed using the Statistical Package for the Social Sciences (SPSS) programme. Frequencies, cross tabulations and case histories were run from this file.

1.7 Strengths, limitations and lessons learnt

The strengths of the project can be seen in its wide stakeholder involvement, consultative formulation of the problem and the mixing of qualitative and quantitative methods for data collection and analysis. The results therefore capture qualitative and quantitative dimensions of the nature and burden of care as experienced by older persons in the context of HIV/AIDS.

The field work also included practical training for a number of field research staff, mostly university undergraduates and health care workers, this practical capacity building exercise is essential in creating a proper understanding of the problem by local people as well as providing a viable resource base for this kind of action oriented research. From a process point of view, the consultation and involvement of national and local government agencies, service providers, NGOs and community leaders has laid a receptive foundation for the ownership of the process, acceptance and assimilation of the findings which would promote responses to the problem.

However, like any other type of empirical research, the study had several limitations. In some areas the charged political environment prevailing in Zimbabwe threatened the security of the research team members. For example, one older man was unwilling to allow his spouse to participate because he felt the study was political and the research assistant was an agent of an opposition party. In some places heavy rains during the fieldwork disrupted the process. Some community members were reserved towards the research team. The reason for this reticence was that previous studies had not benefited these people and therefore they regard such exercises as not relevant to them.

In some instances, the selected persons were not at home when the research team visited. Due to the multi-faceted nature of the care older people provide and the struggle for daily subsistence, interviews were often interrupted because respondents had to attend to the sick, go to the farm or to the market to sell their wares. In such cases the interviewers asked to complete the interview later or accompanied the interviewee to complete the session. Increased incidences of death in the areas due to AIDS meant that some potential respondents were not home when the research team visited because they were preparing and/or attending funerals in the neighbourhood. In a few instances, respondents'

relatives (especially the male spouse) would listen in on interviews, perhaps influencing a few of the older women's responses. In some cases interview teams found themselves in awkward situations when respondents wept during an interview.

However as a pilot project, some important lessons have emerged from the process, these included a recognition to exercise care in designing the research protocol for a mixed methods of qualitative research. Whereas the use of purposive non-stratified sampling is commonly accepted in qualitative research, the results are limiting in a purely quantitative sense, due to the absence of control groups and a sampling based on the whole population.

Another important lesson is the need for thorough training for data collectors. This training should stress the imperative need to interview the defined cases, for example a male spouse who would respond to the questions on behalf of the female main care-giver is unacceptable as his presence and contribution may bias the responses given. In situations in which this would occur, such interviews should not be included in the data analysis. This pilot however provides a basis for improvement on the mixed methods approach as well as useful information for policy makers and service providers on the realities faced by older persons providing AIDS related care.

2

Presentation of main findings and discussion

I am so afraid of what the future has in store for these orphans. If I were to die and leave them, there would be no-one to look after them.

A 62-year-old woman, care-giver of three orphaned children in school in Bulawayo

2.1 Background information and introduction

As shown in section 1.5, a minority of the respondents were not the main caregivers of the PWA. The data indicates that 69.3% of the respondents who were household heads were actually the main care-givers in their households. Interestingly, 108 of a total of 109 older men also identified that their female spouses were the main care-givers while they, the men, played a secondary role. In addition to this, some respondents indicated that other members in the household, or they themselves with the assistance of some other member of the household, were the main care-giver.

TABLE 3. NATURE AND COMPOSITION OF CARE-GIVERS

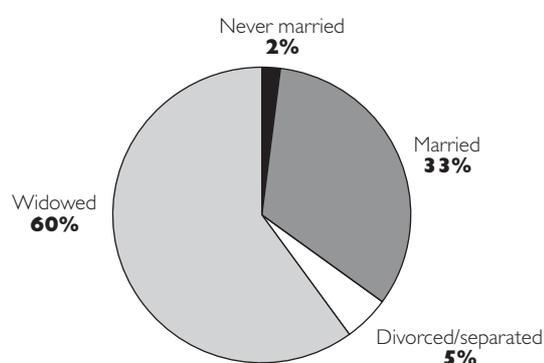
Care-giver	Male	Female	Frequency	%
House-hold				
Head (HHH)	45	430	475	69.3
Spouse	108	1	109	15.9
Son or daughter	4	10	14	2.0
Grand child	2	5	7	1.0
HHH and spouse	24	4	28	4.1
HHH and son or daughter	3	19	22	3.2
Others	12	18	30	4.5
Total	198	487	685	100.0

2.2 Characteristics of sample

2.2.1 Gender of respondents and marital status

In all, 71% of the older persons in the sample were female. Those respondents who were married constituted 33.4% of the sample. The remainder of the respondents had either never married (1.6%), or were divorced/ separated (5.4%), and the majority (60%) of the respondents were widowed, as shown in Figure 3 below.

Figure 3. Marital status and gender composition



2.2.2 Education, livelihoods and religious background of respondents

Of the 685 older persons interviewed, 27.9% had never been to school, 66.6% had some primary schooling and 5.1% had some secondary education. Only 0.4% had high school education and/or tertiary education. The majority of the older persons (52%) were peasant farmers, while 25% were unemployed, 14% were self-employed, and 6% were homemakers. The remaining 3% included unskilled workers, such as farm workers as shown in the Table 4.

TABLE 4. OCCUPATION AND LIVELIHOODS

Main occupation	Number of people	%
Peasant Farmer	356	52.0
Unemployed	171	25.0
Self-employed	93	13.6
Home maker	43	6.3
Other	22	3.1
Total	685	100.0

Only 10.4% reported receiving some remuneration hourly, weekly, biweekly, monthly or periodically, as such, 89.6% of the 685 older persons had neither regular monthly nor net yearly income.

The study further inquired on any other sources of income for these older persons. In rural areas the main livelihood avenues include subsistence farming and market gardening. Other income generating activities included chicken rearing and needlework. In urban areas, older people resorted to activities such as baby sitting/baby minding and ironing clothes to earn some money. Begging for food from relatives also emerged as a fallback mechanism used by some older people.

The majority of the respondents (88.1%) professed to belong to a Christian faith including Roman Catholic, Protestant, Anglican, Methodist, Seventh Day Adventists, and Apostolic Faith/Zion. Of the remaining, 5.4% practiced African traditional religion, 5.3% were Atheists and 1.2% were Muslims.

2.2.3 Household characteristics

The study also established a number of critical household characteristics, including the main source of drinking water, toilet facilities, the main source of energy and type of dwelling unit. This was done to determine the socio-economic circumstances of the respondents. The responses are summarized in Table 5.

Some older persons reported not having access to safe drinking water. As illustrated in Table 5, 12.2% reported that their drinking water came from unprotected sources, such as wells, springs, rivers, streams, ponds, or dams. For those without a tap in their houses, the main concern was the distance to the water source and the possibility of contracting water borne diseases.

The majority of older persons interviewed indicated that they had some kind of toilet facilities. However, 12.4% still use the bush. The main source of energy reported was wood, followed by electricity and paraffin.

TABLE 5. HOUSEHOLD CHARACTERISTICS OF RESPONDENTS

Characteristic	Number of households	%
Main source of drinking water		
Tap in Residence	170	24.8
Borehole with pump ¹	191	27.9
Protected well	132	19.3
Communal tap	62	9.1
Tap on yard/Plot	46	6.7
Unprotected well	57	8.3
Spring/River/Stream	25	3.7
Pond/Dam/Lake	2	0.2
Toilet facility		
Own Flush	201	29.3
Blair ²	310	45.3
Communal Flush	55	8.0
Pit	34	5.0
Bush	85	12.4
Main source of energy		
Electricity	161	23.5
Wood	504	73.6
Paraffin	20	2.9
Type of dwelling unit		
Traditional	111	16.2
Modern	246	35.9
Mixed	319	46.6
Shack	9	1.3

N = 685

¹ Boreholes are devices that drill and pump water deep from the water table.

² Blair toilets are pit latrines with a cover dug out in the ground to prevent human faeces from contaminating water bodies.

In the rural areas the main dwellings were largely traditional pole and dagga huts or sometimes thatched roof houses made of modern bricks. In urbanized areas there was a variety of dwelling units: a combination of traditional huts, modern brick, concrete with tile and roofed with asbestos or aluminium sheets. However, some older persons lived in shacks and dilapidated housing built from makeshift material such as corrugated iron or aluminium sheets, ply woods and other discarded building material. Most of the older persons (90.1%) indicated that they owned their housing units. The remainder, particularly in urban areas, were either tenants, lodgers or lived in shared accommodation.

2.2.4 Household size and composition

Household sizes varied from 1 to 24 members and were divided into three categories as shown in Table 6.

TABLE 6. HOUSEHOLD SIZE

Household Size	Number of households	%
Small (1 to 6 people)	373	54.5
Large (7 to 12 people)	282	41.2
Very Large (13+ people)	30	4.4
Total	685	100.1

2.3 Patterns and extent of care-giving

2.3.1 Patterns and extent of caring for people living with AIDS (PWAs)

You should always be available so that the patient tells you what they want.

A 52-year-old woman in Gwanda

As illustrated in Figure 4, of the 589 older persons who indicated that they were the main care-givers, the highest percentage of them 71.8% (423) were aged 60 years or above.

Out of those living in the 685 households included in the study with a total of 4,540 persons, 198 people were reported as having HIV/AIDS, the majority of whom (61%) were females. As illustrated in Figure 5, sons and daughters made up the single highest group of patients, 6.5% of these sons and daughters were between ages zero and 14 years, while 72.5% were between 15 and 49 years.

Interestingly, 24.2% were heads of households themselves. Of the grandchildren identified as living with HIV/AIDS, 89.3% were between the ages of zero and nineteen years.

Table 7 provides a breakdown of PWAs based on the location. As can be deduced from the table below, the greater portion of the people living with AIDS in the households interviewed lived in rural areas, which is a mix of commercial farms areas, mining towns, resettlement areas and communal

TABLE 7. PWA BY LOCATION

Location	Percent
Urban	22.7
Peri-Urban	2.0
Resettlement	5.1
Mining Town	20.7
Commercial farm	0.5
Communal Area/Rural	49.0
Squatter settlement	—
Total	100

N=198

Figure 4. Older care-givers providing care for PWAs

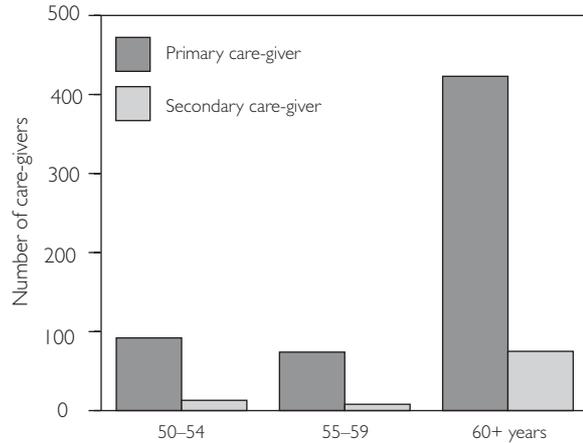
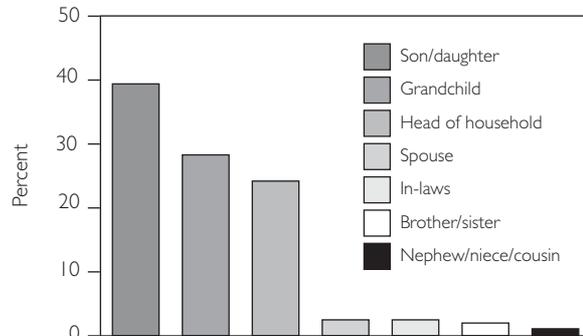


Figure 5. Relationship of PWA to household care-giver



areas (formerly known as native reserves).

It must be noted that people’s HIV/AIDS status was not easy to establish, and the information was exclusively based on community perceptions and/or the knowledge of community health workers and volunteer HIV/AIDS care-givers who were aware from hospital records of the status of their patients. The difficulty here was that people did not volunteer for testing, and in cases where they have been clinically diagnosed, promised confidentiality made it difficult and ethically improper to request access to the records. Even so, there is evidence of denial, probably associated with the stigma attached to this condition, a problem of great concern.

The numerous roles played by older people with respect to caring for the sick ranged from financial responsibilities to psychological support and daily physical care activities. The main daily chores included, boiling bath water, bathing the PWA, ensuring that they wore clean clothes, washing their dirty linen, feeding, turning PWAs in bed and assisting them to access the toilet. Other household chores for the older care-giver include providing the PWA with a variety of foods, encouraging them to

eat, feeding them, and accompanying the PWA to hospital and/or the clinic/doctor. Of particular importance is the act of providing company and continuous care to the PWA including administering drugs and counselling.

2.3.2 Patterns and extent of care for orphans

I am the only surviving adult/grandparent, there is no one to care for the orphans if I don't.

A 66-year-old man, Makoni

I am looking after the children because my son, on his death bed, asked me to look after his kids since his wife had also died

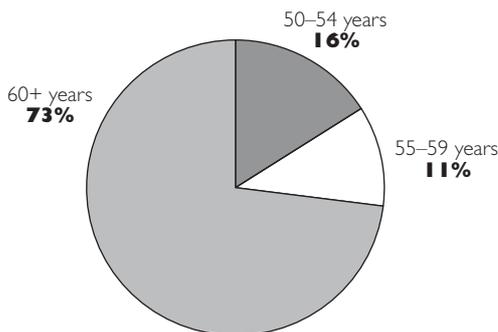
A 53-year-old woman, Gwanda

This study adopted the UNAIDS definition of AIDS orphans: a child who has lost one or both parents to AIDS related death.

The majority of the older persons interviewed were caring for one or more orphans. Eighty six percent noted that they are carers. Only 14 percent indicated that they are not the main care-givers. Further analysis to ascertain the age, rural/urban location and gender of the care-giver established that the main care-givers are aged 60 years or more as indicated in the figure. As indicated earlier the burden of care is generally on the 60 years and higher age group. The figure below shows that a high percentage of 73% of the orphans were being cared for by people in this age group.

The data further shows that 74.2% of all those who were identified as care-givers of orphans were female. The rural urban divide shows that 59.6% of all older persons who indicated that they were

Figure 6. Percentage orphaned children by age of care-giver



the main care-giver of orphans were residing in rural areas.

The highest percentage, 80.5%, were grandchildren of the care-givers. The second largest category of orphans (12.4%) were the care-givers children.

TABLE 8. RELATIONSHIP OF ORPHANED CHILDREN TO CARE-GIVER

Relationship	Number of children	Percent
Grandchild	1462	80.5
Son/Daughter	225	12.4
Nephew/Niece/Cousin	114	6.3
Others	4	0.8
Total	1815	100

Generally, the care of orphans involved providing for the daily and basic needs of children including: food, clothing, shelter, education, comfort and socialisation. This role involved such basics as giving instructions to the children on how to cook and wash. However, as one interviewee confessed, “*Looking after boy orphans can be very difficult. They tend to be so rebellious that in the end we just give up.*” It must be noted that this care is provided mostly in circumstances of diminished or non-existent forms of external support, be it familial or state provided.

2.4 How and why do older people become care-givers: choice or circumstance?

A number of reasons were given to explain the older person’s increasing role as the main care-giver to terminally ill AIDS patients and their ultimately orphaned children. There are three main forms of caring that were identified. In the first scenario, an older person may be caring for a sick relative (mostly a spouse or son/daughter) as well as the PWA’s children (i.e. the care-giver’s children or grandchildren). Upon the death of the PWA the care-giver continues providing care for the orphaned children.

In the second scenario, the older person may be taking care of only a terminally ill adult child, whose children, if any, may be with their other parent, the spouse of the sick person. However, when the PWA dies, the children may be taken to the bereaved family, particularly if the deceased is male – in other words the father. It must be noted that the strong patrilineal inheritance system serves as a bedrock to the family of the male spouse who inherits the children of the marriage upon his death. The parent(s) of the dead spouse therefore often becomes the de-facto care providers of the child (ren).

The third scenario involves the older person who did not provide care for their sick and adult child (who mostly lived in the city or far from home), but after the adult child's death their now orphaned children are brought to their surviving grandparent. This is also sometimes due to neglect and/or abandonment of the children by the surviving parent, due to abuse or due to the children becoming totally orphaned as a result of the death of the other parent. Similarly older people come to care for their children or spouses either because the care recipient was resident with the older person as a spouse or an adult child, or they were living away in the neighbouring town, city or as a migrant in another country (mainly working in the mines and they came back to be cared for).

For most respondents, compassion and satisfaction tend to be mixed with the pain that accompanies care-giving. Besides being emotionally difficult, providing care is not inexpensive. In Highfield, Harare, a 52-year-old woman with an eight-year-old school-going orphan explained that she had had to sell four cows to pay for the treatment of a PWA.

Another desired outcome of caring included being able to give the patient sufficient and unconditional love and attention so that he/she "does not think too much." Respondents noted the need for around-the-clock presence in situations where the PWA could not look after themselves, taxing as it might be. Some care-givers however observed that lack of appetite on the part of PWAs with advanced or full-blown AIDS was a hindrance to providing care, as the carer then had to force-feed the PWA. The undying hope that the PWA would recover was identified as being a major source of inspiration and strength in this daunting task. However in many instances the care-givers played this role merely to pave the way for a dignified death. An elderly informant had this to say, "*Even though I did not foresee my son's recovery, I just wanted him to be comfortable.*" The general consensus was that caring is a sign of love, and that the sick are "too young to die." Older people would do anything "to make the PWA as comfortable as possible, show them that they are still loved and help ease their pain and anxieties so they can have a peaceful death."

The respondents' general view, echoed by the experiences of the research team, supported the notion that no individual or institution was better placed than the older family member to take care of orphans in the absence of their parents. Additionally, the older person often turned out to be not just

the only available, but also the most willing person to look after orphans. There were generally no other relatives in a position to assist, and in cases where such relatives existed, they often lived far away or were unwilling to take on the onerous task of raising someone else's children. "*Other family members were not interested in looking after the orphans,*" said a 79-year-old from Gwanda, with seven orphans, five of whom were in school and two other who had finished school. Reasons outlined for such reticence include the fact that the family members in question were mostly unemployed and therefore unable and/or reluctant to deal with the additional burden of "adopting" the orphans. "*They have their own families and as a result cannot afford the added burden of orphans,*" said a 70-year-old man with two school-going orphaned children in Makoni.

In addition to being compelled to provide care, as was the case for most older people, they felt a strong sense of responsibility: "*It is my responsibility, I am the head of the household and oldest brother in our family.*" This is clear evidence that most old people have no choice and have been forced into these roles because, as heads of households, the responsibilities naturally rest upon them. As one older woman remarked, "*They are my flesh and blood, I cannot turn them away.*" This is a responsibility that is seldom accompanied by the necessary support.

In some circumstances, the PWA on their death bed has asked their parent to take care of the soon-to-be disadvantaged children.

In other extreme cases the children had been taken into the household of the older person because of allegations of abuse levelled against the family of the living parent. One woman came to play this role apparently because her orphaned grandchildren complained of ill treatment from their paternal relatives, and generally felt uncomfortable living with any other relatives except their maternal grandmother.

In some situations, the whereabouts of the children's surviving parent were unknown, or such a parent was a migrant worker from a neighbouring country and could not be traced. For example, a 70-year-old woman with seven orphans in Highfield, Harare indicated that "*Some children were born out of wedlock and others had divorced mothers, so when the mothers died, the children had no one except me to look after them.*" In yet another instance, it was stated that the mother of the orphans lived in Botswana, and that, "*She remarried and deserted her children.*" One older woman expressed ignorance on the

whereabouts of the parent concerned. *“I don’t know where their father is,”* retorted the 65-year-old woman, with four orphaned grandchildren in Seke, Mashonaland East. Conversely, there are cases where *“The mother of the orphans run away with another man,”* noted a 64-year-old woman, with two orphans in school in Bulawayo.

2.5 Older persons attitudes/ feelings about care-giving

Since I am now ill and feel lonely, the presence of orphans in the household helps to ensure I have someone to keep me company. The orphan is the only source of solace for me.

A 59-year-old woman caring for a 13 year old

Orphans need a lot of love, I feel very bad, as my own children can no longer get what they want.

A 56-year-old woman, care-giver for three orphans in Zvishavane

I have no patience, looking after a PWA requires some patience.

A 86-year-old woman caring for two orphans in school in Seke

In terms of burden of care, some older people reported heading very large households, as they care for the sick as well as the children of the sick person. In Seke an 80-year-old Malawian widow reported heading a household of 22 persons, comprising five children aged 30 years or older and 16 grandchildren aged between one and 26 years. She is caring for three sick people: a son aged 36 years; a daughter aged 33, and a 22-year-old grandson. In Njube Township in Bulawayo, a 79-year-old married male head of household is looking after his two sons aged 38 and 54. Both sons lived elsewhere before the onset of full-blown AIDS and had only returned home when they fell ill, a very common occurrence.

In another case a 63-year-old woman from Makoni, whose son and daughter-in-law had died two and five years earlier, respectively, stated that her other son, a 22-year-old and her five-year-old granddaughter were sick. She suspected, from the symptoms, that they were both afflicted with AIDS.

This older woman was widowed and in poor health herself. Other examples included that of a 60-year-old woman, living in Zvishavane, who was caring for her son aged 38 years, a male in-law aged 36 years and a grandson aged 7 years. They were all of Malawian origin, and it was obvious they were all struggling for survival as they did not have the extended family support network they would have had in their own country.

Older people expressed deep feelings about the hardships and cost of caring for orphans. In spite of the hardships caused by the unexpected role they have had to undertake, some care-givers have positive feelings about the presence of orphans in their household. For some the orphaned children were a source of inspiration, they revived welcome memories of the deceased. *“She reminds me of my late daughter, at times I cry when I look at my grandchild”* said a 64-year-old man caring for an eight-year-old schoolchild Gwanda. Orphans give a helping hand as they participate in subsistence and household activities, as stated by an 81-year-old man from Makoni, the guardian of a 15-year-old schoolchild in Manicaland, *“Orphans keep us company and help us in the fields.”*

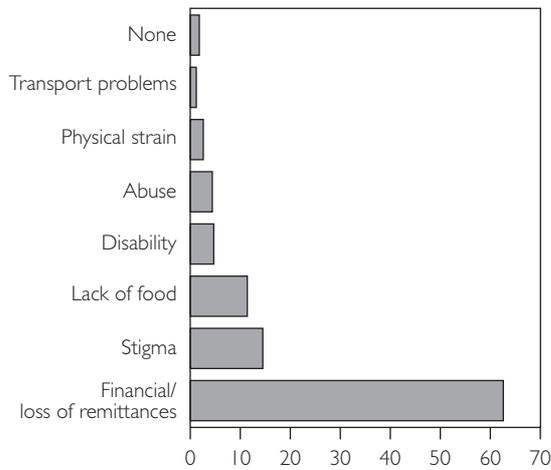
However in spite of this positive view of the presence of orphans in the household, there was an underlying frustration, perhaps resulting from the inability to meet the needs of children orphaned by AIDS. It was stated that the children could bring disharmony into the family. Accommodation has become a major problem especially in households catering to orphans. *“There are many of us now, and there is inadequate accommodation, it is very unhealthy, because there are too many people in this house,”* said a 54-year-old man, Zvishavane.

Although one cannot fully convey the emotional burden resulting from the deaths of their children, grandparents intimated that they were emotionally drained. It is the lack of hope for the future of orphaned children which seems to heighten the pain of grandparents. *“I am so afraid of what the future has in store for these orphans. If I were to die and leave them, there would be no one to look after them,”* said a 62-year-old woman, care taker of three orphaned children in school in Bulawayo.

2.6 Negative Impact of care-giving on the resources, capacity and well-being of older caregivers

The main factors identified by the study that impact negatively on the care-giving ability of older

Figure 7. Main barriers to care-giving



persons is the financial burden of care, the physical demands of care-giving, a lack of knowledge about AIDS-related care, a lack of medicine, the mental and psychological stress of care-giving, a lack of food and other basic needs, poor access to health care for the sick as well as for older care-givers, and socio-cultural issues like stigma, abuse, abandonment and neglect. These are the main impediments that undermine the ability of care-givers.

Figure 7 shows the weighted responses of care-givers; it highlights in proportions of scale the various factors that were identified as inhibiting older people from providing adequate care. These ranged from financial problems and cultural practices to personal problems.

As evident from the figure above, the single most debilitating factor was, without doubt, the financial loss stemming from the drying up of remittances. Without resources, older persons find it extremely difficult to care for both the dying adult son or daughter, and/or the orphaned children. Apart from this, care-givers also had to personally deal with their own fears of contracting the disease, as well as the frustrations inherent in performing the daily chores of cleansing, washing and feeding the PWA and orphans, with no obvious external assistance.

With regard to cultural beliefs, there was usually a strong tendency to believe that the PWA had been bewitched. Very often this tends to compound the already hard financial situation of the household, as the family resorts to consulting traditional healers in efforts to “reverse” what is perceived as a curse, thereby draining a lot of financial and other resources. The patient often dies leaving behind a huge

debt. It is in this kind of environment that the older person is expected to look after the orphaned children.

Consequently, most care-givers confessed that they were burnt out. For example, it was expressed that *“If it is AIDS, then it is difficult to look after the patient because she/he called it upon herself/himself.”* The quality of care depended sometimes upon the nature of the relationship between the care-giver and the patient. *“When the primary care-giver is not a relative then it becomes very difficult to be strongly committed to providing care,”* said a 54-year-old woman, caring for three orphans aged 12, 15 and 16, years in Mbare, Harare.

The various incidences of frustration were, however, reportedly much less incapacitating than the stigma and rejection suffered at the hands of the community. *“People who used to be friendly to me have severed their ties. Now I feel very lonely and dirty”* complained a 76-year-old woman, caring for orphans aged six, 14, 16 and 19 years, all in school, Bulawayo. *“After taking care of three terminally ill daughters, some people in the community no longer want to associate with me,”* expressed a 67-year-old woman in Mzilikazi, Bulawayo with six orphans aged 8, 11, 12 and two 13-year-olds, all in school.

Another major area of concern was stigmatization in either the process of caring for the terminally ill patient, or when there have been a number of AIDS-related deaths in the household. One woman in Seke reported that her home had earned the unflattering label of “heroes acre” following the death from AIDS, of several of her daughters. She had initially found this detestable, but had since learnt to accept the situation and even joke about it.

A 68-year-old man from Seke, explained that stigma was, in fact, often much more difficult to cope with than the act of actually looking after the PWA, *“If the PWA is stigmatised, then it means we cannot effectively look after him/her.”* Many lamented the apparent *“lack of love and sympathy from neighbours”* explaining that another level of stigma emanated from health service providers themselves. Nursing staffs were accused of having negative attitudes towards the sick and their care-givers.

Lack of financial resources was identified as one of the greatest hindrances to older people’s ability to provide adequate and sustainable care. This problem is exacerbated by loss of remittances (due to the incapacitation of the adult son or daughter afflicted with AIDS) and dispossession associated with looting of inheritance resources, which often follows the

death of a breadwinner. This is an instigator of food insecurity. Other barriers to care-giving included disability, abuse, physical strain and transport problems especially to ferry the PWA to and from clinics.

2.6.1 Financial impacts

My sons who were working helped me financially, while my unemployed son worked in the fields. Today no one assists me financially and there is no one to work in the fields.

A 78-year-old woman in Epworth, Harare

Money is the problem especially when the children fall sick. Food has become scarce. The children have lost their inheritance, as relatives took everything, and we have nothing to give these orphaned children. These events have made it impossible to pay rent and electricity bills, and this year we had to move into a shack so that we could at least try to save some money.

A 51-year-old woman caring for three school-aged orphans reported from Mbare, Harare

Sickness and death resulting from AIDS have worsened our financial problems, even though my daughter was not employed. She left her two children with us because she was not married and we are greatly affected as we had to sell some cattle to pay the funeral expenses.

A 75-year-old woman in Makoni area observed

AIDS has negatively affected household composition, income and expenditure, with serious implications for the survival of remaining family members. In most of the households interviewed, there was a recognizable shortage of essential and basic household items such as food, money, clothes, blankets and soap. The needs of PWAs tend to be difficult to meet. People with AIDS require good nutritious food, drugs (which are priced beyond the PWA's affordability) and money for hospital visits. Of equally critical concern was the difficulty experienced in meeting similar needs of orphaned or soon-to-be-orphaned children.

Coupled with this, some households have lost the

savings they had accrued over a lengthy period owing to the prolonged illness of the PWA and the cost of covering their health-care needs before their death from AIDS. This loss of regular income (remittances), increased responsibilities, loss of physical support of children on farms, unpaid bills and the various other demands that caring for orphans involves have increased the stress on older caregivers. Almost in tears, a 90-year-old woman from Seke made the following remark, *"This has been a big blow because the able bodied are no more."* Four of her seven children have died from AIDS-related illness, and the remaining three are unemployed.

The strong correlation between AIDS and poverty makes it difficult to explain which is the causative factor. However, qualitative data strongly suggest that the loss of remittances, economic support and income, and the increase in both financial and non-financial responsibilities due to the death of the most economically productive family members intensify poverty within the already poor household.

Apart from losing their children, some older women have lost their spouses to AIDS, thereby becoming economically handicapped, because in most cases their husbands were the ones with incomes.

In most of the households, respondents intimated that they now regularly experienced critical food shortages, as it had become very difficult to adequately provide food for the family. Generally, inadequate food and clothing, financial insecurity and the inability to meet health needs were identified as the most serious consequences of losing the main income earner.

The general trend however was an expression of regret that an economically productive person had been lost by the household. Generally, the longer the illness dragged on, the more resources were expended. For example, one respondent, a 64-year-old woman, in Mbare, Harare, with four orphaned grandchildren explained her situation as follows: *"The patient suffered for two years at home, our resources have been exhausted."* The deceased had been responsible for paying rent and buying food, among other things. Another respondent echoed the helplessness triggered by a lack of resources: *"This really drained our financial resources,"* said a 61-year-old woman from Seke, who has two orphans, aged seven and nine years, both in school.

It must be noted that not all households had lost a member who was economically productive, suggesting various degrees of financial impact due to

the death of family members by AIDS. Some primary care-givers stated that there was no loss of remittances because their children were either unemployed or had not been sending money home even if employed. Rather, their limited resources had been used to care for the sick, pay for funerals and for the care of orphans. In the words of one respondent a 52-year-old woman from Makoni looking after five orphans, “*there is no loss of remittances because there was none in the first place – I was the breadwinner.*” In such situations, the household and the older person involved have been doubly affected, because their time and savings have been spent on caring for the sick who had not contributed to the welfare of the extended family (household), but returned home after falling ill with AIDS.

With the demise of sources of remittances due to the death or terminal ailment of the economically active person, and the absence of universal pension for older people, the financial burden of care is borne by the care-givers. There was no regular source of income identified by care-givers, except occasional remittances from members of the extended family. In the rural areas where subsistence livelihood was the mainstay, it meant the older persons were not fully integrated into the cash economy. Without having cash, it is difficult to pay for services especially health care services.

In some cases the research team found that sick people were brought back to the “family home” from the city often after years of absence. As already stated in section 2.3.1, 198 people in the sampled households were identified by their care-givers as being terminally ill from AIDS, 76% of these were said to have returned home after they have been diagnosed of AIDS or had fallen ill and needed care. For example, one man who had lived in an urban area and had not communicated with his rural parents in a very long time reportedly made a sudden appearance – he was brought back in a wheelbarrow, suffering from full-blown AIDS. All the same, his elderly mother received him and tended to him with virtually no resources until he passed away.

It must be noted that particularly in Zimbabwe, and for the households most affected, these hardships are compounded by a lack of access to fertile agricultural land by the many rural people – a historical legacy from colonial policy – augmented by poor and rudimentary agricultural practices, lack of access to credit, drought and the attendant cycle of poverty. Remarks by a 77-year-old man from Gwanda were poignant in this regard, “*With an-*

other drought upon us, I don't even know how I am going to fend for these orphaned children.” A 68-year-old woman from Seke in Mashonaland East with four of her six grandchildren in school, and two others out of school said, “*It is very painful. I do not know where to get the next meal for the orphans. We run out of money for food, clothes, and medication for some of the ailing orphans. It is very difficult to be a single parent and worse when there are no rains and the crops are dying. As a result, the family now always experiences acute food shortages.*” Most older people identified a general decline in the standards of living typified by the inability to get enough money to pay rent, feed and clothe the children. Hardships were clearly the order of the day among most of the older care-givers. As an example, a 60-year-old female care provider for two children aged one and four in Mbare, Harare said, “*As for me, I do not even remember the last time I bought clothes for myself.*” The situation is dire as it extends to the nutritional needs of the older persons themselves. As one respondent put it, “*In the whole community, food shortage is now affecting the health of the old care-givers, we no longer have three square meals a day because we cannot afford that.*”

An analysis of household situations reveals that inadequate clothing and food were the most acute they faced. This happens to be the case even among those with a pension, because the pensions are so meagre. “*The little pension that my husband gets is not sufficient to buy food for the children, pay medical bills for the sick and school fees for the PWA's children. Because of such problems, there are difficulties in raising school fees since secondary education is now very expensive,*” emphasised a 71-year-old woman from Highfield, Harare, and guardian to two school-aged children aged 9 and 17.

Households have, however, resorted to a variety of options to solve the cash flow problem. These strategies range from the legitimate to illegal. Testimonies depict great desperation and the lengths to which people have had to go to meet household needs. “*Food is very expensive, and at times I find it difficult to buy even a single bar of soap to wash the orphans' clothes. I have to sell my goats to pay school fees and buy food – life is difficult,*” said a 66-year-old man, in Gwanda, guardian of one orphaned child. A 64-year-old woman, carer for four children aged 2–10 years in Gwanda commented that, “*It has adversely affected us because we are adding another burden to our already cash-strapped household. Actually it is a headache because I have to look after*

them with no additional income or outside assistance.” The level of desperation and lack of avenues for support is shown by the sad experience of a 53-year-old woman from Highfield in Harare whose circumstances appeared very desperate, “I am now forced to sell illegal drugs to raise money to feed the orphans. I am no longer afraid of going to jail.” This respondent was responsible for six orphans, of whom the three older ones were aged 14, 17 and 20 and were in school. The other three aged 8, 10 and 11 were out of school.

2.6.2 Health impacts

We are old and we need someone to look after us and yet we are expected to take care of these orphans.

A 72-year-old woman from Mbare, Harare

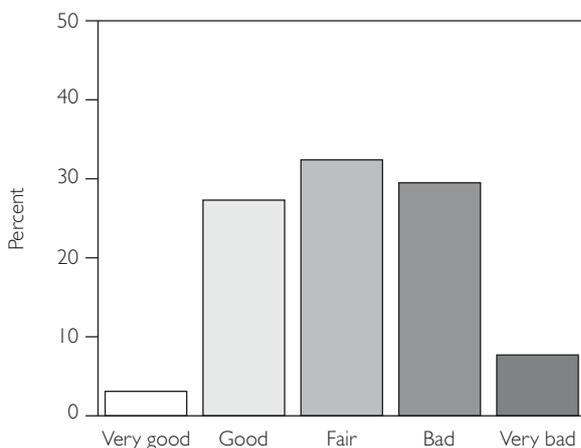
Physical health

The study was designed in such a way as to establish the health problems afflicting older care-givers looking after patients at home. The respondents were therefore asked to rate their own state of health. The responses are summarized in figure 8 below.

On assessing their health and their perception of it, only 30.4% reported being in good or very good health. The remainder reported fair to very bad health status. Of those in poor health, 58.4% attributed it to providing care to others.

The physical and emotional well-being of older people appeared to have been compromised by the increase in daily chores. Older care-givers reported

Figure 8. Older persons’ ratings of their own health



an increase in their activities, which they characterized as having a negative effect on their general health status. Only a few care-givers reported not having been negatively affected by their role in caring for orphans; most respondents indicated the role was a burden with negative financial, physical, health and psycho-social implications.

Respondents were asked whether they had experienced any physical illness during and/or after the death of the person with AIDS. In response, amongst the care-givers, 39% stated that they had indeed experienced physical illness after the death of a PWA they had been caring for. As Table 9 shows, about 25% reported experiencing physical illness during and after the death of a PWA.

The most common physical illness afflicting caregivers was found to be swollen limbs, which accounted for about 26% of all the reported cases of physical illness. This was followed by high blood pressure (BP) with about 24% of all the cases of physical illness. Headaches also accounted for a significant number of cases (about 18%). Most reported headaches were apparently experienced following the death of the PWA.

A considerable number of the care-givers (31%) reported suffering some form of physical illness for the duration of one – two years. Twenty-two percent of the care-givers suffered some form of physical illness for less than a month following the death of the PWA. Of those who suffered for less than a month, about 26% suffered from headaches while 20% suffered from swollen legs/limbs and about 16% of those that suffered for less than a month mainly had high blood pressure.

Amongst the care-givers that suffered for one – two years, swollen legs/limbs (30%) were the main form of physical illness, followed by headaches, BP and dizziness, in that order. The pattern is more or less the same for care-givers who reported having suffered at least five years. Swollen legs/limbs were still the main form of physical illness (about 34%), followed by BP with 28%. Under the ‘others’ category physical illnesses such as eye problems, vomiting, coughing, TB, diarrhoea, herpes and malaria were mentioned.

Overworking has become the order of the day, as older care-givers have no time to rest. A 73-year-old woman, guardian of two orphans in Makoni, Manicaland summarized the experiences of most care-givers in the statement “I have to work extra hard, which I think is quite unhealthy for someone of my age.” Owing to the general inability of most

TABLE 9. PHYSICAL ILLNESS OF CARE-GIVERS

Physical illness	Duration of principal physical illness/complaint						Total
	<than 1 month	1–6 months	7–12 months	1–2 years	3–4 years	5 years and above	
Swollen legs/limbs	12	8	3	30	9	23	85
High blood pressure	10	4	1	15	12	19	61
Headache	16	5	2	16	9	3	51
Dizziness	10	1	—	15	1	5	32
Chest pains	5	1	3	4	—	5	18
Asthma	2	3	1	1	2	7	16
Heart problems	2	2	—	4	4	3	15
Stomach problems	5	—	—	2	3	1	11
Others	5	2	—	11	2	1	21
Total	67	26	10	98	42	67	310

families to cope with their own problems, they tend, often mistakenly, to expect assistance from relatives. As one woman observed listlessly, “*There is no assistance from relatives.*” However, for a few older people, the problem was manageable. This was particularly the case with orphaned children who had an education insurance policy or medical aid covered by a policy taken by their parents while still alive.

The change in lifestyle and responsibilities and the negative effects of providing care were aptly described by a 74-year-old woman who takes care of a grandchild who is in school in Gwanda, “*I feel that my role as a grandmother has changed to that of a mother in so short a time and I am not sure I have the energy to cope. At my age, I cannot continue working because my body is no longer as strong as it used to be. I am totally confused because I don’t even know where to start. I have nothing and my other child who is a soldier does not supports me.*”

With their physical capacity diminishing, older people have found it difficult to work in the fields. Generally, physical tiredness either resulting from work in the fields, especially in the rural areas, or from lack of sleep which was identified as another barrier to care. Some respondents admitted being at a loss about what to do with the orphans. Commonly expressed comments included a 70-year-old woman who was providing for a school-aged child in Gwanda saying, “*It leaves me weak and very tired,*” and a 77-year-old woman with five grandchildren, three of whom were in school in Highfield, Harare saying “*I now have to work very hard despite my old age.*”

Psychological and emotional health

Now I think a lot and find it difficult to sleep well at night

A 68-year-old woman from Gwanda

I am suffering from stress because looking after orphans is very difficult; many times they do not appreciate what we are doing for them. One worries about their future, which affects one’s health. You hardly have sound sleep at night. I have to wake up very early in the morning before dawn to feed the children and work to raise money for school fees.

A 69-year-old woman from Seke, with three grandchildren

Stress and burn-out were described as major barriers to providing care. This was variously described as physical tiredness and insomnia caused by anxiety. Concerning the care of children, an important barrier to care-giving is that children who do not have birth certificates do not have access to state provided services, including school enrolment, welfare, subsidies etc, this is because their nationality cannot be ascertained by the state. The implication here is that the primarily care-giver becomes frustrated with the inability to prove the nationality of the child, due to either non-registration of birth by the PWA who had died, or that the children were brought to the older care-giver without these important documents of citizenship.

TABLE 10. DURATION OF CARE-GIVER'S PRIMARY EMOTIONAL ILLNESS

Emotional Illness	Duration of Illness						Total
	<than 1 month	1-6 months	7-12 months	1-2 years	3-4 years	5 years and above	
Worry/stress	44	21	13	77	27	30	212
High blood pressure	4	2	3	9	1	2	21
Dizziness	1	—	3	6	1	—	11
Others	3	1	—	10	7	1	22
Total	52	24	19	102	36	33	266

Worry/stress was found to be the most common form of emotional illness. Older care-givers had suffered from anxiety over the illness/death of a PWA. Of the care-givers interviewed, 39% (266) reported to have suffered some emotional stress over a period of a year or more. Under the 'others' category, ulcers, insomnia, headaches, and a feeling of being burdened were also mentioned as principal forms of emotional illness. However, in spite of these conditions being known to be medically associated with emotional illness, very few respondents reported on them, perhaps due to a lack of knowledge of this association by the care-givers.

2.6.3 Abuse and rejection relating to care-giving

The sick person sometimes loses his/her mind, when this happens it becomes impossible to provide effective care as they may be abusive and violent.

A 59-year-old woman from Mbare

Verbal abuse from the terminally sick person is a source of worry for me.

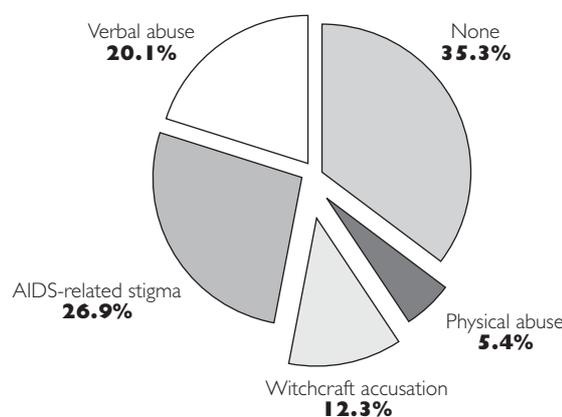
A 51-year-old woman from Zvishavane

About two thirds of the respondents 64.7%, reported to have suffered some kind of abuse, in the form of AIDS related discrimination, stigma, rejection, verbal abuse and physical violence. AIDS related stigma (26.9%) and verbal abuse (20.1%) emerged as the highest form of abuse, and 12.3% had been accused of witchcraft.

Of serious concern to care-givers were incidents of abuse, both physical and verbal from their terminally ill children.

Although these numbers are not large, the pain and loss of dignity inflicted on the caregivers is significant, and in some isolated cases, the abuse

Figure 9. Abuse, stigma and witchcraft accusations



was so acute that the older person had reportedly developed a medical condition. For example a 63-year-old Highfield woman claimed that she suffered a stroke following an incident of abuse which has now impaired her physical ability and quality of her life, as a result she was bitter and heartbroken when the research team visited her.

2.6.4 Potential danger of HIV infection by older people themselves

There are no barriers if you really love the person you are looking after; however it is very difficult to care for your adult son especially when he is still single or when his wife has deserted him or passed away.

A 50-year-old woman in Makoni

Whereas some primary (older) care-giver's expressed that they place no physical barriers between themselves and the PWA's in terms of care-giving although they know of the potential of opportunistic infections, some older care-givers admitted to a lack of

knowledge on the risks related to caring for the terminally ill person. Both groups however stated that culturally, it was unacceptable to be seen as stigmatizing one's own child. Hence, such care practices as using gloves or any other protective item of clothing, (suggesting a layer between the care-giver and the sick) was unacceptable. Accordingly, most older care-givers admitted that they avoided such practices in order not to offend their sick loved ones.

The level of HIV/AIDS-awareness proved to be quite high among the older persons as shown in Table 11. This is an indication that information about the disease had been disseminated to most parts of the country. A number of issues raised in discussions confirmed this high level of awareness. Asked about possible signs and symptoms that could identify those with HIV/AIDS, the older persons noted loss of weight and body weakness, diarrhoea, thinning of hair, skin rashes and sores, TB and coughing, vomiting and lack of appetite as the main signs and symptoms. They also believed that PWAs tended to be ill/bad tempered owing to AIDS-related depression.

On the knowledge of HIV/AIDS transmission, almost 80% of care-givers felt AIDS was transmitted by sexual contact alone, 10% felt it was a mix of sexual contact, blood contact and other causes, However, 10% of the older persons were unable to identify even a single mode of HIV transmission. Additionally, none of the respondents mentioned mother-to-child transmission of HIV/AIDS. Even so, the respondents displayed a high level of awareness of the mode of transmission of the HIV virus.

The respondents also indicated a high level of knowledge of how to prevent the disease – both in relation to self protection and overall prevention (Table 11) However, overall the results show a fairly clear understanding of the message by the public from the Ministry of Health and Child Welfare, and

TABLE 11. CARE-GIVER AWARENESS OF METHOD TO PREVENT ONESELF FROM INFECTION

Method	%
Abstinence	31.4
One sexual partner	17.5
Condom use	13.3
All the above	29.0
Others (example avoid blood transfusion)	2.5
Don't know	6.3
Total	100.0

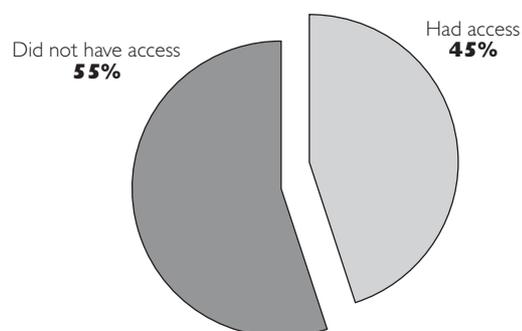
Note: N = 679, 6 missing cases

non-governmental organizations involved in HIV/AIDS projects, – the so-called 'ABC' of HIV: "Abstain, Be faithful to one partner, and Condomise", if unable to follow the first two methods".

However, when it comes to day to day care-giving activities, it is worrying that one third (31.%) did not use any self protection because they are not informed. Of the remaining two thirds of the total respondents that were informed, 51 % reported to use gloves while 13 % used mainly disinfectants, a further 5 % also reported not to use any form of protection.

2.7 Access to and availability of support available to older people

Figure 10. Access to support



Generally the study found out that there is little support available to older people affected by AIDS. When asked **yes or no** as to whether they have any source of support or not, only 45% of the respondents said yes. It emerged that friends, family and churches are the main sources of support.

2.7.1 Health care support

We are old, we cannot walk long distances, we need a clinic to be built nearby. A 74-year-old woman from Makoni explained Even though treatment for older persons is free at the clinics, we also need specialist [private] treatment at times, which is very expensive for us.

A 68-year-old woman from Highfield, Harare

Hospitals should take care of PWAs, not us at home, our homes are not clinics, patients must stay at the hospital, not at home.

A 67-year-old woman from Makoni

As indicated in Table 12, older persons got most of their health care support from health workers. Other health-care providers included volunteer workers, the community and spiritual healers. However, a significant proportion of older persons (24.4%) reported not getting any form of health-care support.

TABLE 12. ACCESS TO HEALTH CARE SUPPORT

Support	% of respondents who had access
Health Worker	61.3
None	24.4
Volunteer care	15.3
Community	11.7
Spiritual healer	11.2
Traditional healer	5.7
Red Cross	0.1
Total	100.1

N = 685

Out of the 625 respondents 361 reported physical illnesses/symptoms as shown in Table 13. A high proportion of caregivers (73%) who had some form of physical illness sought support from hospitals and clinics. Very few people got any support from a combination of traditional and spiritual practitioners.

TABLE 13. SUPPORT FOR CARE-GIVER'S MAIN PHYSICAL ILLNESSES SYMPTOMS

Physical illness	Source of support				Total
	Hospitals and clinics	Spiritual	None	Other	
Swollen legs/limbs	62	3	14	9	88
Blood pressure	69	2	4	8	83
Headache	39	3	9	3	54
Dizziness	23	3	11	3	40
Chest pains	16	1	3	2	22
Heart problems	12	1	2	1	16
Asthma	11	1	1	2	15
Stomach problems	10	2	1	—	13
Other	21	4	3	2	30
Total	263	20	48	30	361
% of total	73	5.5	13.2	8.3	100

In contrast to the overwhelming reliance on orthodox medical care for physical illness/symptoms, there was a much higher reliance on faith based and spiritual support when it came to seeking help for emotional distress almost: 37% (150) of the respondents identified them as their main source of emotional support as shown in Table 14. The great majority of the reported emotional distress (82%) 335 cases was referred to as worry/stress. A few care-

givers sought for emotional support from relatives and combinations of spiritual, medical and traditional practitioners

TABLE 14. SUPPORT FOR CARE-GIVER'S EMOTIONAL ILLNESS/DISTRESS

Emotional illness	Source of emotional support				Total
	Hospital and clinic	Spiritual	None	Other	
Worry/stress	71	138	96	30	335
BP	20	4	3	2	29
Insomnia	6	2	4	2	14
Dizziness	4	2	3	1	10
Other	3	4	11	1	19
Total	104	150	117	36	407
% of total	25.6	36.9	28.7	8.8	100

Churches emerged as institutions of great importance to the respondents. Going to church for counselling and reading the Bible for spiritual and psychological nourishment and well-being were identified as channels for releasing tension and managing stress. It was suggested by some respondents that church members should visit and pray for PWA and care-givers. Some care-givers felt that the problem needed spiritual intervention, and therefore proposed that efforts should be made to invoke the help of spirits of ancestors in protecting the family. Statements like, "People should leave everything to God, He will intervene, because praying is the only answer" and, "care-givers should not despair or lose hope" were indicative of the deep need for psychological and spiritual support for the overworked care-givers. Churches were urged to assist through prayer. "Only God is the great counsellor," remarked one respondent who further suggested that money donated to the church should be used to assist the needy. Faith and dependence on God were recognized as a fundamental pillar, a way of easing the burden. It is important to note that this source of strength is for some older people vital in maintaining their strength and sanity through out the hardships they face.

At the household level, issues surrounding family cohesion and unity were identified as important. The psychosocial well-being of the family as a unit and individually, was identified as being of key importance. Thus, respondents exposed the belief that affected families needed counselling and spiritual support to enable them to accept the problem

related to AIDS and deal with the concerning responsibilities as a unit.

The need for counselling, for both the PWA and the care-giver, was identified. In most cases it was observed that the care-givers should be counselled. With respect to professional counselling, older people complained about lack of confidentiality at counselling services and suggested free access to counsellors. Group counselling and/or counselling for the most affected in the family, especially the primary care-giver, was deemed important. Many household heads believed it was prudent to involve terminally ill people in decision-making on issues that concerned their condition and treatment; to spend as much time as possible with PWA, and; for the community to show kindness and compassion to affected families.

2.7.2 Welfare, economic and social support

In situations of abject poverty, it was suggested that weekly or monthly financial handouts be paid to these older household heads because they have no source of regular income. Generally, people called for an increase in the amount of money given to older persons, and a need for transparency in the disbursement of the AIDS levy to the affected people. At the community and family levels, it was suggested by a 62-year-old man from Makoni, the main care-provider for children aged 11 and 13 years, that through *“burial societies each community member should make a monthly contribution [of approximately \$5.00] to a fund to assist the affected families, and that the extended family should be mobilized to assist with money to look after PWAs and orphans.”*

The government’s responsibility in meeting some of the needs of poor communities is important. The study revealed that very little had been heard of the AIDS levy, therefore calls were made for schemes to be put in place as soon as possible to establish orphan-support networks to reduce the strain on households. It was suggested by a 73-year-old man in Bulawayo caring for four very young children aged three months, six months, two years and four years, that through the Department of Social Welfare, *“schemes should be developed to provide older people affected by AIDS with an allowance similar to the “destitution allowance [public assistance],”* so that they do not starve, beg or depend on their children who are also struggling.

Support from the Department of Social Welfare was described as inadequate or nonexistent. In certain extreme cases, where the drought has limited

the availability of food, people asked for food-aid and clothing, and money to start income-generating projects.

The government was called upon to increase its assistance to the most vulnerable in society by contributing towards school fees, food and clothing for orphans, and helping meet the needs of older persons. The AIDS levy ought to be accessed by older people looking after PWAs and/or children orphaned by AIDS. A practical way of getting the money to older people, it was suggested, would be to deposit some money into a savings bank account to help pay for food, water and electricity bills.

At the time of the research fieldwork, the extreme drought in some of the provinces was posing an additional serious danger to food security and there were calls for assistance involving irrigation to boost crop production.

Suggestions were made for older persons to form groups to grow vegetables and fruit to provide a balanced diet for the terminally ill. Lack of arable land was however considered an impediment to such a project. According to a 60-year-old woman from Bulawayo *“it is now very expensive to buy nutritional food, therefore the government should give us land to grow vegetables and maize.”*

Older persons were wary of the tendency to prescribe income-generating projects to address their financial woes. For example, one care-giver expressed that, *“Please do not tell us about starting self-help projects, because we are old.”* Although this was a general feeling among the very old, some older care-givers optimistically suggested the formation of income-generating projects supported by donors and NGOs, to augment their diminishing household income sources.

Respondents who recommended the launching of small-scale income-generating activities also suggested training and assistance in starting and running micro-credit projects. The training should include saving and investing money from projects. In rural areas, emphasis should be on financial assistance for the purchase of agricultural inputs like seeds and fertilizer to improve yields.

We need education on what home-based care entails; care-givers should be taught how to provide care since their knowledge and advice are minimal.

A 81-year-old man caring for two orphans in Makoni suggests

People should understand that AIDS is just like any other disease.

A 78-year-old woman has cared for two orphans

Importantly, care-givers identified a need for some form of recreation and information about HIV/AIDS through radio, and the involvement of all household members in care-giving activities. It was suggested that women's clubs be promoted to make them readily accessible to female relatives of HIV/AIDS patients and thereby relieve the relatives' psychological burden. Moral support from friends and the community, and recreational facilities for children would help to integrate orphans properly into society.

As such, it was suggested that older persons affected should meet as a support group and discuss their common problems. Younger people in the community should be encouraged to help older persons by performing chores such as sweeping the yard, fetching water and gathering firewood. Extended family members were also urged to assist with material goods like blankets and old clothes.

To eliminate the social barriers that hinder the delivery of care, suggestions were made to improve relationships between generations, group cohesiveness and support, and the welfare of the family unit. In particular, it was felt that much could be achieved through the promotion of burial societies. Blame and stigma were a social burden that primary care-givers felt they did not deserve. They suggested that relatives should not blame the older people by saying that "*we failed to socialise our children well, which is why they got sick and are dying from AIDS.*"

3

Strategies and recommendations for action

The strategies and recommendations outlined here were generated from both the study itself and from the discussion of its results at an Inter-agency meeting held in WHO HQ, (Geneva 28 September 2001) which brought together project stakeholders within and outside the UN system including; experts on care-giving and HIV/AIDS; policy makers; local research co-ordinators; the main objective of the meeting was to review the preliminary findings and provide a summary of main conclusions with a view of establishing strategies for action.

There is an urgent need to address the problems identified by the study through multi-sectoral policies and programmes to sustain the health of older care-givers and to maintain their ability to provide adequate care to their younger family members affected by HIV/AIDS. The following have been identified as the three main areas where actions must be taken to ease the burden of older care-providers:

- a) Enhancing the capacity of older people to look after the sick and/or AIDS orphans
- b) Improving access to and utilization of services
- c) Economic/or income generation and support for older people affected by HIV/AIDS
- d) Improving on the research protocol and conducting further research

a) Enhancing the capacity of older people to look after the sick and/or AIDS orphans

Promote, through public health, the adoption of a paradigm in which the home is seen as an extension of the health-care system. This change in focus and practice will necessitate the transfer of resources such as medicines, equipment, prevention education, training and information on how to provide care to

the home in such a way as to enable home-based care providers to perform their tasks efficiently.

Practical suggestions to achieve this include:

- (i) The promotion of outreach programmes by health-care personnel or specially trained volunteer health workers, which could, for example, include retired health workers. These untapped human resources could be retrained to increase the provision of health-care support to disadvantaged older persons.
- (ii) Improvements in the delivery of services through:
 - Promoting, maintaining and improving the health of older persons-especially those with care-giving responsibilities
 - Providing older people with education/information on HIV/AIDS and related care issues
 - Providing psychological support and counselling for all care providers (health-care workers and home-based care-givers)
 - Reducing double stigma (AIDS-related prejudice and ageism) and other prejudices among health care workers – particularly through their training and education.

b) Improving access to and utilization of services

Although policy actions to recognize and support the contributions of older people are chiefly a responsibility of the government, actions to change attitudes and to provide resources must be multi-sectoral. There is a need to review and analyse all existing policies on available socio-economic assistance programmes for older people. This must be done with an intention of identifying the gaps in their implementation, sustainability, and coordination. Such a review would eventually provide knowl-

edge of the existence and effectiveness of existing schemes.

Another key area for action to be addressed is how to improve access to and utilization of existing social support schemes. Though in theory there are several such schemes, in practice access to and utilization of these services are either low or inexistent. The challenge therefore is how to create conducive systems and environments that would make resources availability to those who need them. If need be, some related laws (such as those on inheritance) must also be taken into consideration or revised. On the basis of this, efforts must be made to create public/official awareness of existing policies and facilitate existing reporting and monitoring mechanisms to ensure that policy intentions are properly carried out at all levels. The mass media, especially radio, may be an important tool in informing the target group on what forms of assistance are available and of ways to access them.

c) Economic/or income generation and support for older people affected by HIV/AIDS

A third identified area for urgent action relates to economic support and security for older people caring for the sick or HIV/AIDS orphans. It was suggested that in the absence of a universal pension scheme, income-generating schemes to support older care-givers should be put in place.

Specific short term issues to be addressed include:

1. The unavailability of drugs in general together with their exorbitant prices have made it virtually impossible for older care-givers to undertake their care-giving duties. There should, therefore, be a visible effort on the part of the government, to provide adequate supplies of drugs (at affordable prices) at the health centres, especially in rural areas.
2. It is recommended that the government put in place structures which ensure that older care-givers receive assistance from the AIDS levy. It should be recognized that while many of the older people might not be HIV-positive, they are one of the groups most affected by HIV/AIDS.
3. Efforts must be made to make accessible to older people adequate and appropriate health services to improve their own health and the well being of the people they are caring for.
4. There must be improvement in the referral system between the home and the hospital and

vice-versa, these two must be integrated and seen as a continuum. In doing this, supervision and support for nurses, CHBC volunteers and social welfare workers is necessary.

5. Psychosocial support both at the individual and community level should be provided, alongside HIV/AIDS education, peer education and counselling.
6. CHBC volunteers must be assisted in a more focused and more systematic manner. These organizations and care-givers require assistance in the form of resources and materials (gloves, disinfectants, blankets) that would enable them to provide safe and adequate care.
7. The government should help older people in both rural and urban areas to start appropriate income-generating projects. These projects could be managed as *Grameen type* community-revolving credit funds with soft loans.
8. There is also a need to assist older care-givers in particular to start support groups and to promote culturally sensitive AIDS education and awareness.

d) Improving on the research protocol and conducting further research

This research has identified the strengths and limitations of the study methodology. Based on these we recommend a comprehensive review of the methodology employed (a mix of qualitative and quantitative methods). This review should take into account the advantages of using such inter-complementary mix of methods as well as the tool-kit that was developed for use by interested countries.

We also call for comparative studies that will include samples of other long term care-giving older individuals for comparative analysis. This may help to further clarify the nature and extent of the burden of HIV-AIDS related care-giving as compared to those related to other forms of care-giving. Such comparison may help in decision making and serve as a basis for resource allocation based on the extent of the burden of care.

Following this revision of the methodology we recommend further studies in Zimbabwe and in other countries deeply affected by AIDS to improve our understanding of the issues involved and to provide a sound basis for policy and programme intervention.

4

Conclusion – the way forward

This report provides evidence on the disastrous impact of HIV/AIDS witnessed every day in Zimbabwe. Clearly, HIV/AIDS patients in the community suffer in a variety of ways. They have little or no access to either affordable and effective health services or to appropriate care and nutrition. Many patients die a lonely, painful and slow death. The home-based care-givers watch them die slowly with nothing to offer. Older persons have now taken on the roles of primary and sole care providers, but without the expertise and resources to render effective care to their dying sons and daughters.

Access to and use of health services were very poor in all areas, due to the extreme poverty of many of the households interviewed. Clearly the problems faced were more than they could bear. Access, restricted by distance and cost, was the main factor hindering the use of health care services. However, the attitude of health staff was also identified as hindering people's willingness to utilise health care services. Complaints made focused mainly on the negative attitude of health workers towards the primary care-giver and the PWA.

Apart from the high cost of treatment, which has further impoverished most households, poor infrastructure and hospital equipment caused major problems. As expected, the psychological problems faced by primary care-givers were a direct result

of the many problems stemming from the rapid increase in HIV/AIDS-related care and deaths. Thus, suggested interventions focused on reducing these problems.

It is evident from the results that older people's health, a clearly neglected issue in Zimbabwe, is of primary importance for the sustainability of the care they provide.

Older people in most African societies are a vulnerable group as a result of a lifetime of hardship, malnutrition, poverty and, in older age, high susceptibility to chronic diseases. The AIDS pandemic is now posing an additional burden on them, further increasing their vulnerability. In their old age, when they may require support and expect to be looked after, they have to take on the role of caring for others, in most cases without even the basic necessary resources. Thus, their health is the most precious asset not only to them, but also to their families and communities. Lack of economic, social and psychological support, combined with poor access to health services, constantly restrict their ability to provide the care expected of them. All efforts must be made to support and address the vulnerability of these older people, not least because it is they who are raising "children orphaned by AIDS" – Africa's future human capital.

APPENDIX I

Background to Zimbabwe: brief socio-economic and political review

Zimbabwe obtained independence on 18 April 1980 after 90 years of colonial rule and a protracted war of liberation. Prior to this, the economic policy ensured white occupation of the urban areas and fertile, commercial farming areas with well-developed infrastructure and high incomes, while relegating blacks to “Tribal Trust Lands” where they depended on a subsistence economy, earning low wages on farms or in industries (Balleis, 1993). These racial inequalities resulted, among other things, in unequal access to social services such as health, education, housing and social welfare. Interest rates, wage levels, exchange rates and the repatriation of profits were controlled as a way of resisting inter-national economic sanctions imposed against the then Rhodesia for its Unilateral Declaration of Independence. It was against this background that, at independence the present government of Zimbabwe inherited a dual economy with some of the worst socio-economic inequalities in the world. Furthermore, the new government inherited a regulated, inward-looking political economy that relied heavily on agriculture and the export of primary goods.

A high concentration of capital and production means was in the hands of the white minority. An estimated 700,000 black farming families lived on 16.2 million hectares of largely poor farm land with low, erratic rainfall in the Tribal Trust Lands, whilst a mere 5,500 white commercial farmers had access to 15.6 million hectares of rich soil (Balleis, 1993). As far back as the 1950s, fears had already been expressed about environmental degradation in the Tribal Trust Lands. The whites consolidated their position of dominance through legislation such as the Land Apportionment Act (1931), the Land Husbandry Act (1951), the Maize Control Act (1931) and the Land Tenure Act (1969) (UNICEF,

1994). The situation was exacerbated by the control of multi-national companies over the economy. At independence the multi-national companies controlled an estimated two thirds of all invested capital.

However, in spite of the adverse effects of the liberation war, the government of Zimbabwe inherited a relatively strong economy that was well diversified in sectors such as industry and agriculture. There was excellent infrastructure and potential for further growth. However, there was an urgent need to redress structural weaknesses in the economy, including inequalities in social service provision (UNICEF, 1994).

Zimbabwe’s independence coincided with the introduction of structural adjustment programmes in Africa. As a result, the new government was under pressure from international agencies to allow market forces more freedom in the economy. However, the government decided not to alter much of the inherited political and economic structures (Kadenge 1993). This stance was at variance with the position of the International Monetary Fund and the World Bank, of which Zimbabwe had become a member in 1980. Instead, the government adopted the “Growth with equity” policy based on the establishment of a socialist and egalitarian society.

According to Kadenge et al (1993) and Chakaodza (1993) economic performance between 1980 and 1985 was characterized by three distinct phases. Phase one (1980 to 1981) was a period of high economic growth and involved the adoption of policies on redistribution. Phase two (1982 to 1983), saw economic decline, while phase three (second half of 1984) witnessed high economic growth that was achieved, through the liberalization of the economy upon independence. The year 1985 saw

Zimbabwe's economic performance improve slightly due to an economic upturn, which had started in late 1984 (Chakaodza, 1993).

In 1985, the government of Zimbabwe published a five-year development plan for the period 1986 to 1990. The plan envisaged a programme of nationalization, broader state economic involvement and a twofold increase in the numbers of peasants, mainly subsistence farmers (estimated at about 50,000), resettled on former white-owned commercial farmland (Gibbon 1995). However, the status quo persisted as economic and social policy maintained the system of economic controls established by the former white regime.

The Zimbabwean government also extended to the whole population social services and employment rights previously preserved for whites. Although limited economic growth was recorded in the 1980s, impressive growth was recorded especially in the health and education sectors. Even government expenditure on social services reflected its commitment to rectifying imbalances and meeting the people's expectations.

By the late 1980s it became clear that Zimbabwe's economic strategies were no longer sustainable. Factors that contributed to economic problems experienced then included a shortage of foreign exchange, which in part led to reduced capital investment in the manufacturing sector. Machinery became increasingly obsolete and difficult to replace. This led to poor performance in industry and limited job creation (Balleis, 1993). The world recession which led to a decline in the demand and revenues from Zimbabwean exports further compounded the problem.

Formal employment had increased from 1,009,900 in 1980 to 1,194 000 in 1990. However, the annual number of about 18,200 new jobs was below the number of annual school-leavers, which had risen from 30,000 in 1980 to an annual average of 200,000 by the end of the decade. In 1991, it was estimated that 27% of the labour force was unemployed.

There was also a large budget deficit, which ran at 10% of the gross domestic product (GDP). The rise in inflation reduced the value of savings and created uncertainty about the stability of the economy, which discouraged prospective investors. This was compounded by the government's strict investment regulations. All this was happening at a time when government expenditure was increasing, as national income generation stagnated. External

debt surged from US\$786 million in 1980 to US\$3,199 million in 1990, while debt service payments as a ratio of export revenue rose from 3.8 in 1980 to 22.6% in 1990. Other factors that compromised economic growth included a high population growth rate of 3.1% per year between 1980 and 1989, a rate not supported by the GDP of 2.7% per year (UNICEF, 1994).

However, by 1989, formal employment in agriculture had dropped by 23.4% to 285,000 workers and the sector's contribution to the GDP fell to 12.4%. This situation was exacerbated by droughts. Failure to adequately redress the imbalances in land holdings due to restrictions imposed by the Lancaster House Agreement aggravated the economy's poor performance because the majority of the black continued to live in areas with poor soils and poor rainfall patterns (Balleis, 1993).

Zimbabwe provided 8,000 troops to help the government of neighbouring Mozambique quell the Renamo uprisings in the 80's. Furthermore, Zimbabwe had to use costly alternative routes to transport its goods, as the Beira Corridor was unsafe. This depleted some of the country's resources. South Africa's retaliatory measures against Zimbabwe's position on Mozambique resulted in socio-economic destabilization. As a result of all these factors, debt service ratio, which was less than 4% of the export earning in 1980, had in ten years accumulated to nearly US\$3,000 million, with the annual debt repayment at US\$473 million, a debt service ratio of 24.5%. (Balleis, 1993).

In October 1990 the government of Zimbabwe adopted the Economic Structural Adjustment Programme policy (ESAP) as a strategy of addressing these problems. The object of ESAP was to revamp the country's ailing economy by promoting sound economic growth based on an increase in exports and the promotion of foreign investment (Mukotekwa, Gumbo and Kamidza 1999). According to the government of Zimbabwe (1998:6), significant progress was made in economic and financial liberalization, deregulation of foreign investment, trade and exchange. But delays in developing and implementing effective strategies for rationalization combined with the negative effects of the 1991–92 and 1994–95 drought undermined the country's ability to effectively exploit the opportunities. Furthermore, the economy had been fraught with the following problems:

1. Budget deficits that exceeded targets

2. Reduction in revenue collecting capacity resulting in revenue falling below planned targets.
3. Inadequate control of expenditure due to unexpected costs related to drought relief, financing of loss making parastatals and slow civil service reform.
4. Devaluation of the Zimbabwean dollar which was in part seen as a way of promoting local products on the local market; yet this made imports more expensive, and Zimbabwe is a net importer of raw material, intermediate and finished goods.

Meeting the costs of these deficits resulted in high inflation and interest rates. The government launched a programme to lower the fiscal deficit to 5% of the GDP. However, by the end of the 1994-95 fiscal year, the budget deficit was 13.5% of GDP (Government of Zimbabwe, 1998:3). It was against

this depressing background that the government of Zimbabwe embarked on the second phase of the economic reforms referred to as the Zimbabwe Programme for Economic and Social Transformation (ZIMPREST), which covered the period 1996 to 2000. The broad aim of ZIMPREST was to overcome obstacles to economic growth and address unemployment and poverty (Government of Zimbabwe 1998:8).

The socio-economic situation of Zimbabwe has, as a consequence of the ESAP, deteriorated sharply over the years. Measures introduced to cushion marginalized groups from the adverse effects of the economic reform programme have had no positive impact. Consequently, the level of poverty has increased since the introduction of the economic reform programme (Mupedziswa, 1997).

APPENDIX 2

National health situation in Zimbabwe

During the colonial era, there was a vertical approach to health care delivery with a focus on curative services. At independence, the government adopted the primary health-care (PHC) approach as a strategy to redress health inequalities, achieve integration and improve access to health-care services. The major goal of the PHC concept was to relocate and decentralize resources from the central and general hospitals to district hospitals, clinics and the community at large.

Between 1980 and 1990, the country's National Health Service was guided by the principle of "Equity in health." Health need and not affordability became the basis for providing health care. In 1986, this concept evolved into the "Health-for-all action plan" whose aim was to address the prevailing health problems in the country. The object was to ensure that all Zimbabweans had access to comprehensive and effective health care.

The government sought to empower the rural population by increasing resources to what was the majority of the population. In line with the PHC concept, the Health-for-all action plan re-emphasized the principles of the PHC approach, focusing on critical elements in addressing the most urgent health needs of the rural disadvantaged. The new approach sought to combine curative, promotive, preventive and rehabilitative services. Access to each level of care was to be achieved by recognizing the appropriate referral system. This required patients to visit the primary level of care as the first point of entry. They would then be referred to the secondary (district hospital), tertiary (provincial) and quaternary (central) level depending on the complexity of their illness.

In-service training was provided for health workers to acquaint them with the new approach to health delivery. Village health workers (VHW)

were trained and deployed in the community. In the early 1980s a means-tested free health service was introduced for the poor, unemployed and those earning less than Z\$150 per month (the official exchange rate was one USD to 51 Zimbabwean dollars (Z\$)). The policy currently applies to those earning less than Z \$ 400 per month. Those aged 65 years and above were entitled to free medical services.

To strengthen these changes the MoHCW was restructured to enable each level of care to support the health-for-all action plan. A new Rural Health Care Division was created in the MOH and was in charge of:

- I. Maternal and childcare and family planning
- II. Expanded programme on immunization
- III. Health education
- IV. Nutrition
- V. Communicable disease control
- VI. Provision of safe water and safe sanitation
- VII. Provision of essential curative care for common conditions and injuries through the VHW at community level
- VIII. Procurement, storage and distribution of essential drugs.

A Mental-health division was established to accommodate postwar traumatic syndromes after the liberation war. All the levels of care were strengthened. A provincial medical directorate was established, as was a district health system (which was to be the basic planning level for implementing PHC activities).

When the ESAP was introduced in 1990, the government introduced the Social Dimension Funds (SDF) to protect the vulnerable in the community. This constituted the basic safety net for the vulner-

able under the Social Dimensions of Adjustment Programme. However, due to increasing demands on the government, the budget for health has continued to decline (Kaseke et al, 1998; Mupedziswa, 1997). Despite the decline in the budget, the devastating effects of HIV/AIDS, the negative impact of ESAP and poverty, there has been a notable improvement in the health-care delivery system. This is evidenced by the broadening of access to health-care services to rural communities. About 85% of the total population now live within eight kilometres of a health facility, as compared to less than 25% before independence in 1980. Life expectancy increased from 56 years in 1980 to 61 in 1990 and however fell to 57 years in 1998 (NHP, 1998).

During the same period, infant mortality fell from nearly 100 to about 66 deaths per 1,000 live births but rose to 80 per 1,000 live births in 1998. The table below summarises important current health indicators.

TABLE 15. CURRENT HEALTH INDICATORS 1990 AND 1998

Indicators	1990	1998
Total fertility rate	5.6	4.3
Crude birth rate per 1,000 pop.	39.48	34.7
Crude death rate per 1,000 pop.	9.49	12.2
Population growth rate	3.1	2.5
Total life expectancy at birth	61	57
Govt. of Zimbabwe total annual health expenditure	44.92	56
Govt. of Zimbabwe health exp. as % of GDP	0.11	2.8
Govt. of Zimbabwe health exp. as % of total Govt. Exp.	5.33	9
Maternal mortality rate/100 000	80	154.6
Infant mortality rate/1,000	83	80
Child mortality rate/1,000	20	36
TB incidence rate/10,000	96.93	370
Clinical malaria incidence rate/1,000	57	139.1
HIV seroprevalence (15yrs & above)	9.2	25
Injuries incidence rate/1,000	49.6	70.5
New cases of disabilities/1,000	—	38
Public sector expenditures in million Z\$	—	712
Population per doctor	7,251	7,811
Population per nurse	765	821
Population per pharmacists	—	23,519

MoHCW: National Health Profiles of 1990 and 1998

According to statistics collected from government health facilities, the most common reasons for outpatient visits today are as summarised in table 16. As can be noted, communicable diseases account for more than half of all outpatient department (OPD) visits to health facilities. Respiratory tract

infections (ARI) are among the leading reasons for visits to OPD, accounting for over a quarter of all new cases (26.8%). Malaria and sexually transmitted infections are second and third respectively. Visits for the treatment of sexually transmitted infections have notably increased from being the sixth major cause of visits in 1996 (5.8%) to being the third most common cause of outpatient visit in 1998 (9.9%).

TABLE 16. TOP 10 OUTPATIENT DIAGNOSES, NEW DISEASES/ CONDITIONS, ALL AGES

Conditions/ diagnosis	% of total new cases
Acute respiratory infection	26.8
Malaria	11.3
Sexually transmitted infection	9.9
Symptoms & ill defined	7.0
Skin diseases	6.7
Burns & other injuries	5.7
Diarrhoea	3.4
Diseases of the eye	2.6
Dental conditions	1.9
Bilharziasis	1.3
All remaining conditions	32.4

Source: MoHCW: National Health Profiles of 1990 and 1998

Chronic diseases account for 27.37% total visits (both new and repeat visits). The most common reasons for chronic visits were Tuberculosis and hypertension. These conditions represented the biggest case load of chronic diseases.

TABLE 17. TOP 10 INPATIENT DIAGNOSES AT DISCHARGE, ALL AGES

Disease/ condition	Cases
Normal delivery	85 656
Malaria	50 667
Pulmonary tuberculosis	30 423
Acute respiratory infections (lower tract)	26 943
Obstetric	19 196
Intestinal infections	19 037
Acute respiratory infections (upper tract)	12 322
Skin & subcutaneous	10 770
Symptoms & ill defined	9 995
Abortions	9 840
Total	490 982

Source: MoHCW: National Health Profiles of 1990 and 1998

Among inpatients, normal deliveries were the main reason for admission over the last 10 years, followed by malaria and Pulmonary tuberculosis. Data on hospital mortality for all age groups high-

light the major diseases facing the country.

The leading causes of infant mortality in hospitals were perinatal conditions, followed by pneumonia. The leading causes of child mortality included malnutrition, diarrhoea and pneumonia. In the adult and adolescent populations, PTB, malaria, HIV-related diseases and Cardiovascular diseases were the leading cause of hospital mortality.

In all age groups infectious diseases emerged as the leading cause of hospital death, followed by HIV/AIDS-related illnesses. Although HIV/AIDS-related illnesses did not appear as the top cause of mortality, they were the underlying cause of about 70% of PTB (see table 18).

TABLE 18. TOP 5 CAUSES OF HOSPITAL MORTALITY, 1998 ALL AGE GROUPS

Diseases/conditions	Cases %
Pulmonary tuberculosis	18.9
Upper tract respiratory-tract infections	12.3
Malaria	11
HIV/AIDS & other viral diseases	8.7
Intestinal diseases	7.5
All other diseases	41.6

The emergence of HIV as a primary cause of ill health has had a major impact on the health status in the country. In Zimbabwe, the first case of HIV-positive infection was identified in 1985, and by 1995, the cumulative number of AIDS deaths had shot up to an estimated 110,000. In 1990, the national seroprevalence among the population aged 15 years and above was 9.2%. By 1994 it had doubled to 18% and the figure further increased to 25% in 1995. In 1990, a total of 26,840 patients of all ages died of HIV/AIDS. This figure increased to 124,071 in 2000 and is projected to rise to more than 137,000 in 2005. (MoHCW: National Health Strategy Document, 1997).

According to the UNDESA (2001), Zimbabwe is among the five worst HIV/AIDS affected countries together with Uganda, Zambia, Botswana and Malawi. It was projected that HIV would soon account for 75 childhood deaths/1,000 live births per year (MoHCW: National Health Strategy Document, 1997).

In 1998, a total of 7,291 new AIDS cases were diagnosed and 288 (about 4%) of the patients were aged 50 years and above. The highest figures (5,102 cases or about 70%) were reported between the ages

BOX 2. WHO/UNAIDS ASSESSMENT OF THE EPIDEMIOLOGICAL SITUATION IN ZIMBABWE, 2002

These estimates include all people with HIV infection, whether or not they have developed symptoms of AIDS, alive at the end of 2001:

Total (adults and children)	2,300,000	
Adults (15–49)	2,000,000	Adult rate (%) 33.7
Women (15–49)	1,200,000	
Children (0–15)	240,000	

Estimated number of adults and children who died of AIDS during 2001: **200,000**

Current living orphans (under age 15 as at end of 2001): **780,000**

HIV prevalence among ANC attendees tested during the 2000 HIV sentinel surveillance survey at 19 sites distributed across the country was 35%; sixteen sites had rates exceeding 25%. HIV infection rates ranged from 25.7% to 70.7%. Comparing the HIV prevalence of 1997 and 2000 at the 10 sites used in both surveys, median HIV prevalence increased from 27.4% to 36.1%. In 2000, ANC attendees aged 15–19 years had an HIV prevalence of 27.8%, the 20–24 year-olds had a rate of 35.1%, and the 30–34 year olds had the highest rate of 43.5%. HIV prevalence was higher among women living in commercial farming areas (43.7%) and in growth points (38.3%) within rural areas. In the major urban areas, HIV prevalence among antenatal clinic attendees tested increased from 10% in 1989 to 36% in 1994.

In 1997, 30% of antenatal clinic attendees tested HIV positive. Age detail is available from Harare in 1995 only: 26% of antenatal clinic attendees under 20 years of age tested positive for HIV, including 28% of women 15–17 years of age. Outside of Harare, sentinel surveillance information among antenatal clinic attendees is available since 1990. HIV prevalence among antenatal clinic attendees tested has increased from 12% in 1990 to 37% in 1995; in 1997, a median of 30% of antenatal clinic women tested in 31 sites were HIV positive. In Masvingo in 1995, where 42% of antenatal clinic attendees tested were HIV positive, 34% of women less than 20 years of age were HIV positive. Peak infection in the Masvingo site occurred among women 20 to 24 years of age with 49% testing positive for HIV. ANC surveillance survey was conducted in 2001 and the results will be available around June 2002.

In 1994–95, 86% of sex workers tested in Harare were HIV positive. In Harare, HIV prevalence among STI clinic patients tested increased from 52% in 1990 to 71% in 1995. Outside of Harare, HIV prevalence among STI clinic patients increased from 6% in 1987 to 72% in 1996. Antenatal clinic women at the 19 sentinel sites were screened for syphilis with Trepanoma Pallidum Heamoagglutination test (TPHA) during the 2000 HIV sentinel surveillance survey. 5% of the women screened had a positive syphilis serology. Women in the age group 35–39 years had the highest rate of 12.8%.

UNAIDS/UNICEF/WHO (2002) Epidemiological fact sheets on HIV/AIDS and sexually transmitted infections, Zimbabwe: 2002 Update, UNAIDS Geneva.

TABLE 19. NEW AIDS CASES, ARC, STD AND TB CASES, 1990–1998

	1990	1991	1992	1993	1994	1995	1996	1997	1998
AIDS cases	4557	8180	9174	10647	13356	12029	6732	7291	4362
ARC	—	15760	17383	22872	20062	26430	19780	9924	10572
STI	963436	1240596	878366	879307	813698	873218	864494	828876	828653
TB	9132	12198	15237	20125	23959	30831	35735	43762	47077

Source: MoHCW National Health Profile 1990 and 1998

of 20 and 49 years. Table 19 summarizes new AIDS cases, AIDS-related cases (ARC), STI episodes and TB cases from 1990 to 1998.

There is a strong correlation between HIV/AIDS and the incidence of STIs and TB. Since STIs increase the risk of HIV infection, high prevalence rates have been reported among STI and TB patients in recent times. Studies conducted at the sentinel sites show that seroprevalence among STI patients ranges from 24% to 60% (National Health Strategy Document for Zimbabwe, 1997). AIDS-related conditions such as cryptococcus, herpes, Karposi's sarcoma and malnutrition are on the increase. The health sector has mounted several AIDS-awareness programmes, targeting vulnerable groups. The government has also introduced an AIDS levy and a national policy on HIV/AIDS has been put in place. Despite these efforts, STI and TB cases continue to escalate.

Several NGOs have implemented initiatives aimed at those already infected with HIV. Organized home-based care programmes have been increasing steadily throughout the country. Most families in Zimbabwe have experienced at least one death due to AIDS. The stigma associated with the diagnosis of HIV affects all family members, and people with HIV/AIDS are still denied benefits, discriminated against in the work place and marginalized.

While HIV/AIDS deaths mainly occur in the 20–49 year age-groups, for older people, the major challenge of this epidemic is in providing care for the AIDS orphans. The National AIDS Coordination Programme (NACP) projected that there would be a total of 600,000 orphans by the year 2000. A study conducted in Masvingo and Mwenezi showed that the majority (56.4%) of care-givers for orphans were in the 50-years-and-above age group (Matshalaga, 1997). The elderly are left to fend for

such children with meagre resources, and the increased dependency ratio at household level exacerbates their poverty. Indeed, migration and the ravages of the AIDS epidemic have reduced the number of economically active people in sub-Saharan Africa available to support each older person, causing enormous societal strains (Longman, 1999).

There have been several negative effects of HIV, including:

- i. Increased morbidity and demand for health and social services
- ii. Increased absenteeism from work, with reduced productivity
- iii. Increased mortality especially among the under fives and young adults (20 to 40 years)
- iv. Increased orphans, single parents and families headed by children
- v. Increased psychological stress and economic pressure on individuals and families.

Nothing much has been done for older persons, therefore much has to be done in relation to PHC and older people. With the breakdown of traditional structures, in which the immediate family usually takes care of older persons, the Ministry of Health and Child Welfare has noted the need for a programme specifically for older persons.

In the national health strategy document, the Ministry of Health and Child Welfare has indicated the need to raise the awareness of the public and health personnel of the needs of older persons. A policy has been put in place, *inter alia*, entitling anyone above 65 years and invalids to free treatment in government hospitals, courtesy of either their Medical Aid Society or the Social Development Fund.

APPENDIX 3

The situation of older people in Zimbabwe

According to the 1992 census, the proportion of the Zimbabwean population aged 60 and above stands at 5.0% (or 513,014 people) distributed evenly between males and females. The proportion of older persons has been rising perceptibly in Zimbabwe owing to an increased life expectancy and, most importantly, a decline in fertility rates (CSO, 1998). Since women tend to outlive men, and by and large are much younger than their husbands, the number of widows at advanced ages significantly affects the social structure of older people. Consequently, problems related to employment, income adequacy, health, welfare, living arrangements and patterns of social interaction of the older people may affect older women more than men (Weeks, 1992).

The CSO (1994) noted that in Zimbabwe, international migration was negligible. Therefore, the 1992 population projections were based on fertility and mortality alone. Assumptions on fertility and mortality were used to produce four possible sets of projections, each covering a five-year period between 1992 and 2007. On the whole, there were no marked differences in the total projected population between these sets. The projected population by the year 2007 ranged from 16.6 million for the first set to 17.1 million in the fourth set (see Table 20 below).

TABLE 20. POPULATION AGED 60 YEARS AND ABOVE 1992 TO 2007

Year	Male	Female	Total	% change
1992	257 826	266 900	524 726	—
1997	262 901	269 436	532 337	1.45
2002	291 817	321 415	613 232	15.2
2007	317 264	447 910	765 174	24.78

Source: CSO, 1995

Table 20 gives absolute projected statistics on the elderly population between 1990 and 2007. Generally, there is a projected increase in the population of older people, particularly women. The percentage age change between projected years also indicates this increase, which is estimated at 46% between 1992 and 2007.

Data from the 1992 census suggest that life expectancy at 55 is 18 years for men and 21 years for women. Life expectancy at 75 years of age is five years for men and seven for women. This means then that despite the HIV/AIDS epidemic, the majority of people who managed to reach 55 years are likely to survive in old age. Improvements in mortality at older ages can contribute significantly to the ageing of the older population itself. Johnson and Falkingham, (1992) stress Bourgeois-Pichat's suggestion that if fertility is at or below replacement level, mortality changes can cause population to age from the apex rather than the base of the population pyramid. This means therefore, that in the Zimbabwean context, ageing of the population is possible from both the base and the apex. (Longman, 1999).

Despite the HIV/AIDS epidemic, available data suggest that while AIDS reduced the size of the population, the decrease was less than might be expected. The population of Zimbabwe, which was estimated to be 11.8 million in 1997 (CSO, 1998), is projected (in spite of AIDS) to increase to 13.8 million by 2005 and to 19.3 million by 2025.

AIDS primarily affects those in the more economically productive age bracket of 20–49 years, who accounted for 70.4% of reported AIDS cases between 1989–92 (National AIDS Control Programme, NACP 1993). People aged 60 years and above were reported to constitute 1.48% of all the reported cases during this period, while the 50–59

years age group accounted for 4.8%. Reported cumulative AIDS cases between 1987–97 indicate that those aged 60 years and above accounted for 1.9%, while those in the 50 to 59 age group accounted for 3.8% of all cases (NACP, 1998). Thus, compared to the overall AIDS cases, the incidence for aged persons is minimal.

Care for older persons in Zimbabwe is of particular concern. Proposals were submitted to the Zimbabwean government in 1994 to establish a clear policy for the care of older people. The 1994 proposed legislation covered, among other things, family-focused social welfare services, the promotion of community-based care, protection of older persons as consumers, their continued employment, income security and education. A bill was revised, redrafted and forwarded to the Parliamentary Committee on Legislation for further scrutiny, and, if passed by Parliament, will become the Aged Persons Act. The bill was subsequently referred back to the National Council for amendments. Existing legislation to address some of the needs of the older population include: the Social Welfare Assistance Act of 1988; the Disability Act of 1992; the Private Voluntary Organization's Act and the National Social Security Act with respect to the Pensions and Other Benefits Scheme.

The Department of Social Welfare in the Ministry of Public Service, Labour and Social Welfare has the main responsibility for the welfare of older persons. This department collaborates with other line ministries, including the Ministry of Health and Child Welfare, Ministry of Local Government, Rural and Urban Development and some NGOs. Today, NGOs dealing with the welfare of older persons include the National Council for the Aged in Zimbabwe and HelpAge Zimbabwe, both of which are involved in advocacy for support to older people. The OAK Foundation carries out information programmes on HIV/AIDS and related matters.

Poverty is a major challenge in Zimbabwe,

particularly among older persons. The majority of older people do not have formal education. They lack basic necessities (food, shelter, clothing, blankets, and clean drinking water). Among older people in urban areas, high prices for houses, high rentals, electricity and water bills are major concerns. In rural areas, most of the huts are decrepit and fuel wood is scarce.

For older people who had been gainfully employed, retirement has often meant a drastic reduction in their monthly income. The devaluation of the Zimbabwe dollar in line with ESAP prescribed by the International Monetary Fund and the World Bank has seriously undermined pension schemes by eroding real value. Pensioners are among the worst hit by the adverse effects of the Economic Structural Adjustment Programme on the bulk of Zimbabwe's population. Thus, the majority of older persons lack financial resources. Current social security measures in Zimbabwe are limited in coverage and scope because only those who retire from employment or on private pension benefit from some form of social security.

Health service centres and clinics are inaccessible to the older people owing to factors such as long distances and shortages of drugs. No particular importance is attached to the health of geriatrics in the country; thus the health system tends to overlook the health of this section of the population. The majority of older persons residing in rural areas survive in conditions of poverty and squalor. A few old people's homes exist but mostly in urban areas, the very concept being alien to older indigenous Zimbabweans who have always had the family to look after them. However, family set up has now been weakened considerably by modernization, urbanization, industrialization and a host of other factors. This is the nature of the environment in which older people have to confront the effects of HIV/AIDS in Zimbabwe today.

APPENDIX 4

Brief profiles of study sites

A. Matabeleland south province:

Gwanda district

Gwanda district is situated some 125 kilometres south of Bulawayo (the second largest city in Zimbabwe) and is divided into Gwanda town, Gwanda South and Gwanda North. The district has a total population of 154,775 (according to the 1992 census). Employment opportunities in the district are very limited. About 80% of the population live in rural areas and depend largely on agriculture for a livelihood. Gwanda district is serviced by 25 health facilities. There are 10 rural health centres, five mine/ industrial clinics, a health post and an urban health centre which offer primary health care. The other clinics offer specific services or have a selected target group namely, ZNFPC, prison, police camp, army and a school. There are three hospitals in Gwanda: Manama, Mtshabezi and Gwanda Provincial Hospital. These hospitals offer both primary, secondary and tertiary services. Lack of specialists and adequate facilities force the hospitals to rely on Bulawayo for specialized care. Two private practitioners are based in Gwanda town. Some of the community members also consult traditional healers for their health-care needs.

Gwanda district is divided into 23 wards, each covering four to six villages. The team visited 10 wards (ward 4, 5, 6, 7, 8, 11, 14, 15, 17, 21). In Gwanda North, villages visited included Sibona, Sithezi, Gongwe, Hwanke, Mtshabezi, Simbumbumbu, Mapane, Magumbo, and Wabayi. In Gwanda South, Manama, Bengo and Mabantu villages were visited.

B: Bulawayo city: Mzilikazi suburb

Bulawayo is the hub of the two provinces of Matabeleland, which comprise the whole of western Zimbabwe from the South African border in the south to the Victoria Falls in the north. The

1992 census estimated the population to be 786,606. Bulawayo is the second largest city and is one of Zimbabwe's principal industrial centres.

Several health centres service Bulawayo. Nearly every residential area has a clinic or hospital (mostly privately run). Mpilo General Hospital, United Bulawayo Hospitals, Ingutsheni Hospital and Mater Dei, a private hospital, are the three referral hospitals. These service the greater part of Bulawayo, other regions of Matabeleland and Mberengwa district. In brief, health services were offered in 18 static clinics, seven outreach clinics and three hospitals. Other health services are maternity, family planning, cytological, child-health, diet-patient, psychiatric and dental services.

Mzilikazi, a high-density suburb, is one of several residential areas in Bulawayo. Mzilikazi is one of the oldest residential areas in that city and perhaps partly for this reason, the suburb has a large population of older people. It was in this suburb that a sample for Bulawayo was drawn for the study.

C: Harare province

According to the CSO Harare, the capital of Zimbabwe, in 1992 had a population of 1,485,615. The urban part of Harare comprises 99% of the total population of Harare Province. The rural section of Harare, the only rural district in the province constitutes 1% (21,600) of the total population of Harare. Sixty six percent of the population is economically active. A small proportion (0.44%) of the economically productive population consists of communal workers.

The main hospitals in Harare are Parirenyatwa and Harare Central Hospitals, both referral hospitals. The city of Harare has two infectious diseases hospitals, Beatrice Road Infectious Diseases Hospital and Wilkins Infectious Diseases Hospital, both run by the local authorities. There are also a

number of private hospitals, which include The Avenues Clinic, Southend Hospital and St. Anne's Hospital, as well as numerous private nursing homes, catering mainly for the terminally ill. Due to the magnitude of the HIV/AIDS problem, these hospitals, especially the infectious diseases hospitals are often full beyond capacity.

The city of Harare 1999 Annual Report notes that in 1999 15,949 deaths were registered at the Harare District Office compared to 14,421 in 1998, an increase of 10.5%. The leading causes of death for all ages were as follows: pneumonia (22.1%), tuberculosis (15.8%), HIV-related causes (12.3%) gastroenteritis (6.2%) and malignancies (5.9%). In all 5,483 deaths occurred at home in 1999 alone.

D: Mashonaland east province: Seke communal lands

Seke is situated in Mashonaland East Province. The Province is divided into nine rural district councils, namely Chikomba, Goromonzi, Hwedza, Marondera (Rural) Mudzi, Murehwa, Mutoko, Seke and Uzumba/ Maramba/ Pfungwe. Seke has 24 wards and the study was carried out in the following wards: Ward one Nemasanga, Ward three Mapfuti, Ward four Mandedza and Ward six Zhakata.

Seke has a total population of 75,178. The district is largely rural, with small sections of peri-urban areas, such as Epworth, along its border with Harare City. Seke has a surface area of 2,587.29 square kilometres and a population density of 29 persons per square kilometre.

The 1992 census showed that 23,764 persons were economically active while 5,842 were unemployed in Seke. Some of the economically active were in formal employment in Harare. Many were involved in communal farming while others were in the informal sector. National AIDS Co-ordination Programme, of the Ministry of Health and Child Welfare estimates the cumulative HIV/AIDS cases for Seke for the period 1987 to June 2000 as 7353. This breaks down into: Females 3,170, Males 3,152 and Unstated 31.

Mashonaland East has: one provincial hospital with 178 beds; five district hospitals with 497 beds; one special hospital with 52 beds; five mission hospitals with 430 beds; and one private hospital with 45 beds. Of these, only Kunaka Hospital is in Seke district. Some people living in Seke use Chitungwiza Hospital. However, there are also several clinics scattered throughout the district.

E: Midlands province: Zvishavane urban

Zvishavane shares boundaries with Mberengwa, Chivi, Filabusi and Shurugwi district. The 1992 population census put the population of Zvishavane at about 98,738. The current survey was undertaken only in Zvishavane urban, mainly because the researchers wanted to capture the impact of HIV/AIDS in a mining community. In Mandava suburb, community life is similar to that in a mining compound: toilet facilities are shared and rooms are overcrowded. Other areas visited, apart from Mandava, were Maglas and a squatter settlement outside Maglas suburb.

Zvishavane has the highest rate of HIV/AIDS infection in the Midlands Province. According to information gathered from the Department of Social Welfare, HIV/AIDS patients, half of whom have full-blown AIDS, account for 75% of bed occupancy in the local hospital. In all 50% of the deaths in the District Hospital were HIV/AIDS-related and 75% of outpatients were suffering from diseases related to HIV/AIDS.

There are 12 public health institutions including a large mine hospital. These include five rural district centres, seven government health institutions (among them a district hospital). The Zimbabwe Red Cross Society has volunteer workers who assist families affected by HIV/AIDS. The volunteers also assisted the team in identifying respondents.

F: Manicaland province: Makoni district

Makoni district in Manicaland Province covers 8,200 square kilometres, with a population of 257,012. Ninety percent of the population in the district reside in rural areas, and only 8% in urban areas. Sixty percent are in communal areas, 20% in resettlement areas and 12% in large-scale commercial farming areas.

In Makoni district the researchers covered seven wards namely Sangaro (ward 6), Matohwe (ward 18), Nyamungura (ward 19), Zurura (ward 20), Ruombwe (ward 21), Dumbamwe (ward 22) and Headlands – Nyamera Farm (ward 26). The local councillors, notably those for wards 19 and 26, helped the research team in identifying eligible respondents. In some cases the researchers sought help from the village headmen. A large-scale commercial farming area was also covered.

There is an HIV/AIDS programme in Makoni, which is operational in urban areas alone, and not in rural areas. The programme was spearheaded by an organization called Family AIDS Counseling Trust (FACT).

APPENDIX 5

Study questionnaire

Impact of HIV/AIDS on older persons in Zimbabwe

Good morning/afternoon. My name is Mr/Mrs I am working on a research project on the Impact of HIV/AIDS on Older persons in Zimbabwe. This is a joint project of the University of Zimbabwe, The Ministry of Health and Child Welfare and the World Health Organisation, whose results may be used for planning purposes. I would like to ask you some questions about yourself and your immediate family. Some of the questions may be sensitive, but I would like to assure you that everything you say will be kept confidential and your name will not be used in any public document. You have been selected at random to participate in this study. Your honest participation will assist in meeting the objectives of the study.

Unique Identifier

Please ensure that each box /question is completed. Mark each box “” with an “x” where appropriate.

Observer name

Date (dd/mm/yy) Time start Time finish

Province	Name of district/area and type	Village/suburb
<input type="checkbox"/> Harare	<input type="checkbox"/> 1. Urban	
<input type="checkbox"/> Bulawayo	<input type="checkbox"/> 2. Peri-urban	
<input type="checkbox"/> Midlands	<input type="checkbox"/> 3. Resettlement	
<input type="checkbox"/> Manicaland	<input type="checkbox"/> 4. Mining town	
<input type="checkbox"/> Mashonaland East	<input type="checkbox"/> 5. Communal area	
<input type="checkbox"/> Matabeleland South	<input type="checkbox"/> 6. Commercial farm	
	<input type="checkbox"/> 7. Other:	

Questionnaire was administered in what language?

- English
- Ndebele
- Shona

Section A
I. Household composition

Line no.	Name of usual h/h member <i>Start with head of household</i>	Relationship to head of h/h* Relationship 1. HH, Head 2. Spouse 3. Son/daughter 4. Parent 5. Brother/sister 6. Nephew/niece/cousin 7. Grandchild 8. Inlaws 9. Not related	Sex 1. Male 2. Female	Age	Marital status 1. Never married 2. Married 3. Divorced/separated 4. Widowed	Ethnic origin 1. Zezuru 2. Karanga 3. Ndebele/Kalanga 4. Manyika/Ndau 5. Shangani/Venda 6. Korekore 7. Other (specify)	Is father by birth alive 1. Yes 2. No	Is mother by birth alive 1. Yes 2. No	Religion 1. Roman catholic 2. Protestant 3. Moslem 4. Pentecostal 5. Apostolic faith/ Zion 6. African trad. 7. Religion 8. Atheist
01									
02									
03									
04									
05									
06									
07									
08									
09									
10									
11									
12									
13									
14									
15									
16									
17									
18									
19									
20									

Section B. Education/occupation/income

2. Highest level of education obtained (or number of years of education?)	3. Main occupation/livelihood (munoita basa rei)	4. Pay cycle (munotambiraswa riini)	5. Net income (munotambira marii)	6. Other sources of income (average Zim\$ per week)
<input type="checkbox"/> None <input type="checkbox"/> Some primary (1–7) <input type="checkbox"/> Some secondary (8–11) <input type="checkbox"/> High School (12–13) <input type="checkbox"/> Tertiary 14 Plus. <input type="checkbox"/> Completed University <input type="checkbox"/> Other	<input type="checkbox"/> 1. Self employed <input type="checkbox"/> 2. Farm worker <input type="checkbox"/> 3. Domestic labourer <input type="checkbox"/> 4. Unskilled worker <input type="checkbox"/> 5. Miner <input type="checkbox"/> 6. Skilled worker/artisan <input type="checkbox"/> 7. Technical/ clerical service <input type="checkbox"/> 8. Professional/ manager <input type="checkbox"/> 9. Home maker <input type="checkbox"/> 10. Peasant farmer <input type="checkbox"/> 11. Unemployed	<input type="checkbox"/> 1. Hourly <input type="checkbox"/> 2. Weekly <input type="checkbox"/> 3. Biweekly <input type="checkbox"/> 4. Monthly <input type="checkbox"/> 5. Other, specify: <input type="checkbox"/> 6. N/A	N/A	

7. What are the roles of the older person in the household activities?

A

B

C

D

E

Section C: Living arrangements:

8. Main source of drinking water	9. Toilet facility	10. Main source of energy	11. Type of dwelling unit	12. Tenure status	13. No. of rooms
<input type="checkbox"/> 1. Tap in residence <input type="checkbox"/> 2. Tap on yard/plot <input type="checkbox"/> 3. Communal tape <input type="checkbox"/> 4. Borehole <input type="checkbox"/> 5. Protected well <input type="checkbox"/> 6. Unprotected well <input type="checkbox"/> 7. Spring/river/stream <input type="checkbox"/> 8. Pond/dam/lake <input type="checkbox"/> 9. Non-treated tap water	<input type="checkbox"/> 1. Own flush <input type="checkbox"/> 2. Blair <input type="checkbox"/> 3. Pit <input type="checkbox"/> 4. Bush <input type="checkbox"/> 5. Communal flush	<input type="checkbox"/> 1. Electricity <input type="checkbox"/> 2. Wood <input type="checkbox"/> 3. Paraffin <input type="checkbox"/> 4. Gas <input type="checkbox"/> 5. Coal <input type="checkbox"/> 6. Other	<input type="checkbox"/> 1. Traditional <input type="checkbox"/> 2. Modern <input type="checkbox"/> 3. Mixed <input type="checkbox"/> 4. Shack <input type="checkbox"/> 5. Other	<input type="checkbox"/> 1. Owner <input type="checkbox"/> 2. Tenant <input type="checkbox"/> 3. Lodger <input type="checkbox"/> 4. Tied accommodation <input type="checkbox"/> 5. Other	

Section D. HIV/AIDS awareness questions

14. Have you heard about HIV/AIDS? 1. Yes 2. No

If No Probe. If definite that interviewee has no knowledge then skip to Q. 21.

15. How is HIV/AIDS transmitted	16. What causes AIDS	17. How can you protect yourself from infection	18. How do you protect yourself from being infected by an HIV person you care for	19. Do you have access to any of the health care support below?	20. What are the signs and symptoms of AIDS?
<input type="checkbox"/> 1. Sexual contact <input type="checkbox"/> 2. Up to God <input type="checkbox"/> 3. Blood contact <input type="checkbox"/> 4. Don't know <input type="checkbox"/> 5. Others	<input type="checkbox"/> 1. HIV virus <input type="checkbox"/> 2. Women/ men <input type="checkbox"/> 3. STDs <input type="checkbox"/> 4. Up to God	<input type="checkbox"/> 1. Condom use <input type="checkbox"/> 2. One sexual partner <input type="checkbox"/> 3. Abstinence <input type="checkbox"/> 4. Taking preventive medicine <input type="checkbox"/> 5. Choosing partners safely <input type="checkbox"/> 6. Avoid blood transfusion <input type="checkbox"/> 7. Others	<input type="checkbox"/> 1. Use gloves <input type="checkbox"/> 2. Disinfectants <input type="checkbox"/> 3. None <input type="checkbox"/> 4. Don't know	<input type="checkbox"/> 1. Health worker <input type="checkbox"/> 2. Volunteer care <input type="checkbox"/> 3. Community <input type="checkbox"/> 4. Spiritual healer <input type="checkbox"/> 5. Traditional healer <input type="checkbox"/> 6. None	

21. Has a member of the household suffered from chronic illness or died recently? 1. Yes 2. No

If no skip to Q.23.

22. What in your opinion could have caused these?

23. How many people have HIV/AIDS in this HH (Line no.)	24. Duration of illness in months	25. Did the PWA live elsewhere before being ill? <input type="checkbox"/> Yes <input type="checkbox"/> Returned ill <input type="checkbox"/> Returned within 2 years but before being ill	26. Was PDA/PWA a breadwinner for the HH <input type="checkbox"/> Yes <input type="checkbox"/> No
a. b. c. d. e. <input type="checkbox"/> None	<input type="checkbox"/> N/A	<input type="checkbox"/> N/A	<input type="checkbox"/> N/A

* Maternal or paternal grandmother (MGM or PGM)/grandfather (MGF or PGF), aunt (MA or PA)/uncle (MU or PU), brother/sister.

APPENDIX 5. STUDY QUESTIONNAIRE

27. Number and sex of orphaned children due to chronic illness resulting in death of one or both parents. (Line no.)	28. Age(s)	29. Relationship	30. Orphan in School or not <input type="checkbox"/> Yes <input type="checkbox"/> No
<input type="checkbox"/> None	a. b. c. d. e. f. g. h. <input type="checkbox"/> N/A	<input type="checkbox"/> N/A	<input type="checkbox"/> N/A

Section E. Care-giving

31. Who is (are) the main care-giver(s) in this household	Write line no.
---	----------------

32. What are the roles of the older person in care-giving activities?

33. What are the desired outcomes for providing care to PWAs and people with other chronic illness?

34. What are the main barriers that prevent effective care (Stigma, Violence, abuse, disability, loss of inheritance and /remittances etc.)

35. Indicate relationship of subject (indicate if subject is household head/primary care-giver/etc.) to persons with HIV/AIDS and orphaned children*.	Write line no.
---	----------------

36. Are there any household members lost to AIDS related illness and death	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No
--	---

37. If so, to what extent has this affected remittances on household livelihood opportunities?
(Explain)

38. Are you part of an NGO/community programme supporting your terminally ill children or their orphaned children?	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No
--	---

Section F. Caring for orphans

39. How does the presence of orphan's impact on the household and the older carers?

40. Indicate what is involved in caring for orphans
(Code and prioritise under value 1 for most and 7 or least)

41. Care responsibility	Rank priority
Emotional	
Financial/monetary	
Social/cultural	
Spiritual	
Educational	
Physical	
Other	

42. Is the older person the main carer of orphans?

- 1. Yes
- 2. No

If yes why?

Financial burden of caring for orphans (seek priorities 1 most etc. code)

43. What are the main issues involved in caring for orphans?

44. Expenditure item	Rank in order of most expensive	Estimated cost per year
Clothing		
Health		
Education		
Food		
Other		

45. What are the health needs of the orphans in this HH?

46. How are these needs met?

47. Indicate scope and amount of time spent in care-giving activities during PWA illness

Type of care provided	No. of times per day	Other sources of assistance

48. Is the older caregiver physically disabled?

- 1. Yes
- 2. No

Specify

49. Did the caregiver experience any physical/emotional/mental illnesses within last year? Indicate before, during or after PWA death. Please list in the table below

Illness/condition	Duration	Support	When?
Physical (specify)		Hospital Clinic Traditional healer None Spiritual Other, Specify	Before During After
Emotional (Specify)		Hospital Clinic Traditional healer None Spiritual Other, Specify	Before During After
Mental (specify)		Hospital Clinic Traditional healer None Spiritual Other, Specify	Before During After

50. Do you get any support ? 1. Yes 2. No

If no skip to Q. 52.

51. If yes, where do you and other caregivers get this support?

Type of support	Source of support
Financial/economic	
Social	
Emotional	
Spiritual	
Physical caring	
Other	

52. What are your health needs in caring for the terminally ill person?

53. How would you rate your health? **If in good health skip to see Q. 56.**

- 1. Very good
- 2. Good
- 3. Fair
- 4. Bad
- 5. Very bad

54. If in poor health, would you attribute it to the caring activities you perform? 1. Yes 2. No

Section G. Access to health care services

55. What are the main services used in the care of the terminally ill and orphans (formal, informal, private, and community based)?

56. Explore and identify barriers to access and utilisation of services (financial, attitude of staff, transport, stigma)

57. Explore their perceptions of service delivery

58. How far is it to the nearest Health Centre?

- Less than 5 kilometres
- Between 5 and 10 kilometres
- More than 10 kilometres

61. How much do you pay for Health-care services?

- None
- Less than Z\$100
- Z\$101 to Z\$500
- More than Z\$500

59. What is the main mode of transport?

- 1. Walk
- 2. Wheel Barrow
- 3. Scotch cart
- 4. Car/ vehicle
- 5. Other (specify)

62. Is this affordable to the family?

- 1. Yes
- 2. No

60. How much do you pay for transport to and from the Health Centre?

- None
- Less than Z\$25,00
- Z\$25,00 to Z\$50,00
- More than Z\$50,00

63. How would you describe health provision and services in your area?

- Very good
- Good
- Fair
- Bad
- Very bad

Section H. Violence and abuse related to HIV/AIDS

64. Have you experienced incidence of any of the following stigma, violence, abuse, witchcraft accusation in this family due to your association with AIDS?

- | | | |
|-----------------------|------------------------------|-----------------------------|
| Issue | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Violence | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Abuse | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Witchcraft accusation | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Stigma | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

If no skip to Q. 66.

65. Which institutions/individuals do you turn to when faced with such difficulties ?

Difficulty/problem	Individual affected Line no.	Organisation, institution or individual you approach for help
Stigma		
Physical violence		
Abuse (verbal)		
Witchcraft accusations		
Others (specify)		

66. What in your opinion can be done to ease the burden of AIDS on the primary carer?

67. What in your opinion can be done to ease the burden of AIDS on the household.

68. What could be the sustainable and effective interventions to support and improve the ability of the older persons to provide care?

Item	Intervention
Financial	A
	B
	C
	D
Health	A
	B
	C
	D
Psychological	A
	B
	C
	D
Social	A
	B
	C
	D

69. In your opinion, what immediate strategies need to be in place to provide support to the household and family caregivers in home based care

70. Do you have any other comments or questions pertaining to this interview?

NB: Now record your impression and observations from the interview you have just conducted.

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