COPING STRATEGIES OF FAMILIES LIVING WITH INDIVIDUALS SUFFERING FROM HIV/AIDS: A CASE STUDY OF KASAMA URBAN AND PERI-URBAN

BY

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DECLARATION

This dissertation is the original work of Elson Muulu. It has been prepared in accordance with the guidelines for MPH dissertations in the University of Zambia. It has not been submitted elsewhere for a degree at this or another University.

Signature: .... Date: 13·06·03

CERTIFICATE OF COMPLETION OF DISSERTATION

I, **Elson Muulu** hereby certify that this dissertation **"coping strategies of families living with individuals suffering from HIV/AIDS. A case study of Kasama urban and peri-urban"** is the product of my own work and, in submitting it for my MPH programme, further attest that it has not been submitted in part or in whole to another University.

Signature: .... Date: 13·06·03

(Student)

I, DR S. SIZIYA having supervised and read this dissertation, am satisfied that this is the original work of the author under whose name it is being presented. I confirm that the work has been completed satisfactorily and is ready for presentation to the examiners.

Signatures/supervisors.................................... Date: 13/6/03

Head of Department: .... Date: 13/6/03

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DEDICATION

This dissertation is dedicated to our only daughter **Lusyomo Mutinta** who was born hardly a month before I commenced the MPH studies.

ACKNOWLEDGMENTS

My sincere gratitude go to Dr. S. Siziya for the guidance and supervision of the entire dissertation.

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Also I say thanks to all the home based care focal persons who assisted me not only in locating the households of the study subjects but in data collection as well.

LIST OF ABBREVIATIONS

AIDS - Acquired Immunodeficiency Syndrome

HIV - Human Immuno-Deficiency Virus

HBC - Home Based Care

NGO - Non-Governmental Organization

WHO - World Health Organization

SAFAID - Southern Africa AIDS Information Dissemination Service Bulletin

UNAIDS - Joint United Nations Programme on HIV/AIDS

DFID - Department of International Development

OPERATIONAL DEFINITIONS

For the purpose of the study, the following definitions were applied:

1. **Coping Strategies/Mechanisms**

   Responses to the stresses and shocks arising from the HIV/AIDS impact.

2. **Community Support Structures/Systems**

   Deliberate set organisations or institutions, associations, clubs and groups for provision of care and support to HIV/AIDS individuals and their families.

3. **Opportunistic Infections**

   Infections that take advantage of a weakened body immunity.

4. **Family**

   Conveniently used for relatives or group of people staying together with an individual suffering from HIV/AIDS eg nuclear or extended family, friends living with an AIDS patient etc.

5. **HIV/AIDS Patient**

   Registered patient with an organization providing home based care and has been diagnosed to have AIDS by a health provider.

6. **Care provider/Caregiver**

   A person who renders care to a sick person in the family.

7. **Potential Caretaker**

   A person who would be in a position to provide care to a sick person if there happened to be one in the home.

ABSTRACT

OBJECTIVE: to determine the problems and the coping strategies of families living with individuals suffering from HIV/AIDS.

DESIGN: Cross sectional study and Focus Group Discussion (FGD).

SETTING Kasama urban and peri-urban in the Northern Province of Zambia.

SUBJECTS: The subjects consisted of 106 caregivers randomly selected from families living with individuals suffering from HIV/AIDS who were under home based care programme. Of these caregivers 56 were drawn from the urban area and the rest from peri-urban.

The FGD was composed of 10 participants who were neighbours to the families living with HIV/AIDS patients.

MAIN OUTCOME: Availability of resources that enable families cope with the care of HIV/AIDS patients, knowledge about the disease, and skill of care for HIV/AIDS patient.

RESULTS: One hundred and six home-based caregivers were enrolled for study. The majority of them experienced lack of knowledge and skill for care (85.8%), lack of medicines (97.2%), food (98.1%) and money for school (98.1%) which hindered them to cope with the care of individuals suffering from HIV/AIDS.

Most (55.7%) caregivers believed that living with HIV/AIDS patients posed risk of contracting the HIV infection. Lack of knowledge about the disease and lack of protective materials were the major reasons mentioned for great risk of infection transmission.

While some (35.8%) families did nothing at all/depended on God for protection against contracting HIV infection from the patients they lived with, others (19.8%) employed patient isolation (not sharing a room with the patient).

Other ways of coping with the problems of HIV/AIDS patient care identified, among others, included begging from relatives (50.9%) change of residence by patients, Selling of family assets (38.7%) and depending on charitable organizations (14.2%). The charitable organizations included the Catholic Church, Kasama Centre for Children in Crisis, and the Northern Province Health Education Unit.

The study also revealed that under coverage (37.7%) by the community support system constituted a major problem in the provision of support to the families living with HIV/AIDS patients.

The common support, rendered to the 66 families who received assistance, included counselling (57.6%) and materials (53.0%).

The focus group members revealed that the community was more sympathetic with families living with individuals suffering from HIV/AIDS than they used to be in the past. This was attributed to the fact that the disease was not only common in the community but most people appreciated its burden on the family. While the focus group believed that HIV/AIDS was a less disease of shame on the family the HIV/AIDS patients, especially in the late stage of the disease, tended to be selective as to who visited them.

CONCLUSION: Lack of resources such as food, medicines, money, materials and knowledge about the disease and skill of care made it difficult for families living with HIV/AIDS patients to cope with their care.

CHAPTER ONE

1.0 INTRODUCTION

1.1 BACKGROUND INFORMATION

Living with one of the family members suffering from an acquired immuno-deficiency syndrome (AIDS) (a syndrome caused by the Human immuno-deficiency virus infection) is cause enough to change one's life in one-way or the other dramatically.

Family members, just like the AIDS patient, may have to adopt certain coping strategies to meet the psychological, social and economic implications of the disease.

To some people, this period strengthens them as they face these challenges and threats, while others fail to cope successfully and remain dependent on community support structures such as hospitals, home-based care centres run by either Government or non-Governmental Organizations.

HIV/AIDS pervasive impact on the social and economic development has been more severe in developing regions of the world especially Africa than elsewhere. World Health Organization (1999) has revealed that Africa is the epicentre holding about 23.5 million out of 33.6 million people living with the disease. Africa also accounts for 13.8 million out of 16.3 million deaths of adults and children due to HIV/ADIS from the beginning of the pandemic in 1980s to close of the twentieth century.

While studies show a disproportionately higher prevalence rate in women than men, there are more men than women dying from HIV/AIDS in the sub-Saharan Africa population. For instance Gregory and Garnett (2000) in a SAFFAIDS report on Zimbabwean National mortality shows a 250% and 150% increase in the male and female adult death rates respectively over the period 1988 and 1994. Whether such HIV/AIDS mortality statistics and research findings reveal the true picture of the epidemic or not the burden of the disease on the family and individual remains evident and a public health problem.

A particular problem created by the deadly disease is the high number of women and children headed households with minimal support systems in place. Zambia, like most countries in the sub-Saharan region, has been hard hit by the HIV/AIDS epidemic. According to Central Board of Health (1999) an estimated 19.7 percent of the entire adult population aged 15 to 49 years is currently infected. Unfortunately most of these people do not even know their HIV status (Ministry of Health, 1999).

The Ministry of Health (1999) further reports that 923,000 adults and nearly 87,000 children have been infected since the beginning of the epidemic to 1998, of whom more than 600,000 persons may have developed AIDS. The HIV/AIDS/STD/TB council (2000) also has noted that HIV/AIDS related deaths are rapidly escalating, and expected to peak in 2005.Life expectancy is plummeting with the average Zambian lifespan dropping from 54 to 37 years.

The high levels of poverty, which increases people's risk environment for acquiring the disease, have compounded the HIV/AIDS situation in Zambia. According to the living condition monitoring survey (LCMS 1996) 78% of persons in Zambia were poor, with the majority 66% being extremely poor. The poverty levels were so high that the households in Zambia reduced the food intake/meals (55%) and household items (46%) as coping strategies. UNAIDS (2000), unpublished study, also observed that out of every ten Zambians seven live in abject poverty and almost every second household is unable to feed itself properly. Unemployment is another outstanding poverty-related problem. LCMS further shows that more than 1 in every 3 females in the labour force was unemployed (35%), as compared to about 1 in every 4 males (24%). Moreover HIV/AIDS exacerbates poverty as well. For example families affected expend scarce family resources on any HIV/AIDS cures-both modern and traditional medicines, special diets, transport to and from health facilities etc. Consequently this often compromises the economic well being of the family unit.

In view of the inadequate family resources the patient may not receive the decent care deserved. This assertion is supported by Kambilumbilu (2001 personnel communication) who believes that the needs of the HIV/AIDS patient have out weighed the economic capacity of the households in the country.

As one of the mitigation activities for economizing on AIDS health care spending at both national and family level community/home-based care is being promoted country wide through District Health Management Teams and collaborating non-governmental organizations.

Kasama Urban and Per-urban are some of the areas in Kasama district with AIDS patients on home based care programmes. The programmes are being run by various organisations under Kasama district health services. Although home-based care programmes exist, Foster (1997) has observed that under-coverage of the AIDS cases in Zambia by the current home based care programmes has been retrogressive in improving the care and support of the patients.

1.2 STATEMENT OF THE PROBLEM

The diagnosis of HIV/AIDS usually brings untold misery to the individual as well as the family. Plans and dreams are shattered, as anxious moments set in. Fears of stigmatization, contracting infection, long suffering, costs of care, and eminent death bring about immense psychological stress.

The misunderstanding of the disease, by the family or community, quite often leads to non-acceptance of the chronically ill individual. According to Hangton, family's or community's understanding of the disease is key to acceptance of the chronically ill individual. This assertion has been echoed by Chyme (1986) who believes that an individual suffering from a terminal illness, and does not require speciality treatment, can be managed at home if the family understands the nature of the disease. This implies that if the family understands the nature of the disease and the basic management, the sufferer can be taken care of at home. This reduces on the frequency of hospitalization, its associated costs and the fears of contracting the infection.

While the diagnosis of HIV brings untold misery to the individual, Central Board of Health (1999) states that the severe impact of HIV on the family begins to be felt when the infected family member gets into the AIDS phase of the illness and starts to suffer from repeated opportunistic infections. A breadwinner's illness, in particular, leads to loss of income, loss of family productivity as the individual is unable to work and sometimes-family members spend working hours caring for the sick.

While home-based care has its own advantages such as cutting down government expenditure on health care, creating hospital bed space for other patients it must be appreciated that it has its own demands, which may break down the family. Quite often families have to strive to meet their needs and also provide decent care to the AIDS patient using limited family resources.

The cost of treating AIDS patients is prohibited to the majority of Zambians. The study by the World Bank (1997) indicates that the average direct cost of treating an AIDS patient from the time of diagnosis until death range from US$ 100 TO US$ 1,100 in Africa.

As though the management of the chronically ill at home is not burden enough, more or even worse problems follow after death of the chronically ill especially if it involves one of the spouses. The problems of the widow or widower and quite often orphans start to take their toll.

Property grabbing, withdrawal of children from school, children being cared for by frail and elderly persons and stigmatization of the surviving spouse have been the common phenomenon.

With the introduction of home based care programmes in Zambia HIV/AIDS patients get discharged from health facilities "prematurely". Also there seems to be an increase in the number of individuals brought in dead (BIDS) to health care facilities. For example in 2001 University Teaching Hospital (UTH) recorded approximately 1,068 BIDs, inclusive of HIV/AIDS associated deaths, with an average of 28 BIDs per day (UTH Annual BID report, 2001).

These observations reveal that the longer period of suffering and provision of terminal care to HIV/AIDS individuals take place in the homes. It is also clear that there are few, if any, nursing homes or hospices to act as alternative institutions of care for the sick in the community. Even if the alternative institutions were available it would not make any difference since the majority (78%) of the people in Zambia are poor (CS0, 1996).

1.3 JUSTIFICATION

The study, therefore, attempts to uncover uncover the problems and the coping strategies of the families living with individuals suffering from HIV/AIDS. Many studies conducted on HIV/AIDS and the interventions mainly focus on the prevention of the spread and treatment of HIV/AIDS (Macdonald et al, 1990); the impact of HIV/AIDS on the national economy (Chingámbo, et al, 1998) and Health Delivery System in Zambia (Foster, 1993, unpublished study)/ other HIV/AIDS related study is on death rates, resultant increasing number of orphans associated problems of their care (Hunter and Foster, 1998, unpublished study). None of the above cited studies have addressed the issues affecting the carers of the HIV/AIDS individuals. While other deliberate care and support systems such as the Home-Based Care for HIV/AIDS patients and counselling groups do exist, there is much to be desired about the needs of the family members living with the HIV/AIDS individuals.

The results emanating from the study will be beneficial to organisations and individuals involved in the provision of care and support to the HIV/AIDS patients, and ultimately the recipients of care (HIV/AIDS patients, and ultimately the recipients of care (HIV/AIDS patient and the family) , by:

(i) Increasing family awareness of the existing community support systems and consequently enhance their accessibility.

(ii) Adopting appropriate coping strategies, which will enable them develop capacity to handle the implications of the HIV/AIDS impact.

1.4 HYPOTHESIS

Families living with individuals suffering from HIV/AIDS are coping with their care.

1.5 OBJECTIVES

General Objective

To determine the problems and the coping strategies of the families living with individuals suffering from HIV/AIDS.

Specific Objectives

1. To determine whether families living with HIV/AIDS individuals are stigmatised by community members.
2. To determine whether family members hold fears of contracting HIV infection from the HIV/AIDS individual they live with.
3. To measure the constraints associated with the care of HIV/AIDS individuals at home.
4. To establish the common sources of support for families living with individuals suffering from HIV/AIDS.
5. To identify the kind of support families living with HIV/AIDS individuals receive from the existing community support systems.
6. To make recommendations on the interventions of assisting families living with individuals suffering from HIV/AIDS.

CHAPTER TWO

2.0 LITERATURE REVIEW

Coping strategies

Miller and Kaene (1972) define coping strategies as conscious or unconscious strategies or mechanisms that a person uses to cope with stress or anxiety. Some of the general coping strategies to stress include: turning to a comforting person for love and support, turning to God, self discipline, acting on for working off tension, talking and expressing feelings by laughing and also use of unconscious defensive mechanisms.

According to Carney, coping strategies of families with AIDS patients are responses to stress and shocks that tend to bring about food and livelihood insecurity. In this context livelihood is defined as capabilities, assets that are both material and social resources and activities required for means of living.

They further postulated that the coping strategies of families are dependent on whether the shocks and stresses are sudden or chronic. Poor households are likely to have more difficulties in coping and are vulnerable to the impact of HIV/AIDS than households with more assets (including human and financial). This assertion is supported by Topouzis and Guerny (1999) who have observed that the ability to cope with the implication of the HIV/AIDS impact mainly depend on the family's economic and socio-cultural conditions and status. It has also been documented that coping strategies are less effective in families with fewer assets than families with more assets.

The World Bank (1997) suggests that households respond to the impact of AIDS (and other shocks) using three coping strategies which involve; altering the household composition, drawing down on the savings or selling assets and utilizing assistance from other households under informal and formal institutions.

Topouzi and Guerny (1999) hold the same views with the World Bank and outlines the coping strategies to HIV/AIDS impact as: Liquidating savings accounts or stores of value; Taping obligations from extended family or community members; depending on charity, breaking up of household, distress migration; and reverse migration.

Lepage, et al (1996) believe and suggest that women and children are the highly vulnerable groups within a household to the impact of AIDS. Therefore, quite often they are the ones that have to respond to the stresses and shocks of the HIV/AIDS.

For instance women take on a double burden of production and caretaking. In certain instances their labour is reallocated from income generating outside the home to taking care of children. The effects of HIV/AIDS on the children lead to increased number of orphans, homeless children who end up living on the streets and withdrawn from school to substitute for adult labour.

Community Support Services

Families affected with HIV/AIDS usually receive assistance from the extended family and clan, neighbours, community groups such as churches, savings clubs and local organizations. The kind of support and mitigation activities vary from organization to organization and is either material or labour and finance in rare occasions.

Family's Perception of HIV/AIDS

Individuals' misconception about HIV/AIDS usually leads to unnecessary fears about HIV transmission and AIDS. Studies on young people's perception about HIV/AIDS reveal that they worry about AIDS. Millsten, et al, (1997) observed that one in four pre-adolescents mentioned AIDS as their primary worry and major concern.

Fears and perception of risk may foster adherence to protective behaviour. According to Millsten, et al (1997) individuals who either do not perceive themselves at risk or deny risks of illness are less likely to adopt health-protective behaviour. However, increased anxiety or fear of an illness may prove overwhelming to an individual, causing one to worry unnecessarily about non-risky situations and actions.

On the other hand, Moore and Rosenthal state that, excessive fears may foster counter phobic behaviour where individuals, feeling overwhelmed by fear, may deny the relevance of an illness to them personally or engage in reactive risk taking.

Stigmatization

The degree of social stigmatization against HIV/AIDS patients varies from society to society. Stigmatization may occur at family or and community level.

Some acts suggestive of stigmatization among others include; Rejection of an HIV/AIDS patient; leaving nobody to give terminal care during the last phase of the illness; Loss of work; loss of home and even loss of life.

According to WHO (1999), HIV/AIDS is highly stigmatized in India and stigma is more often against women than men. As in many countries, the association between HIV/AIDS and 'promiscuous' sexual behaviour has created a belief that people who are infected with HIV somehow 'deserve' their fate. This view is supported by the survey findings in Central Africa Republic that nearly one in every five flatly mentioned that AIDS patients deserve no care and should be killed. Anarif (1999) found similar sentiments in Ghana that sufferers of the disease must be killed or at best confined.

Other schools of thought indicate that HIV/AIDS stigmatization in most parts of the African continent is less prevalent now than it used to be in the earlier days of the epidemic. This has been attributed to the fact that almost every family has been affected by HIV/AIDS directly or indirectly. This has been echoed by Kaijage (1999(who states that people are therefore generally more sympathetic to persons with AIDS and it is less a disease of shame than it used to be the case in Kagera, Tanzania.

Another study conducted in Rakai district in Uganda reveals that AIDS patients are little stigmatised except by adolescents, who think that since the means of transmission is known, people have only themselves to blame if they fall ill.

It has also been documented that the rejection of an HIV/AIDS patient by family members is usually based on the previous poor relationships and not on the diagnosis itself. However this kind of rejection can be changed through counselling and it has been observed to be successful in many cases (Lewis, R. F et al 1995).

CHAPTER THREE

3.0. METHODOLOGY

The following variables were considered in the study:

- Coping strategies
- Education
- Source of income
- Family relationships
- Family size
- HIV/AIDS counselling
- Community support systems or structures
- Family perception of HIV/AIDS
- Fear of HIV infection

3.1 Study Design

The study was a cross sectional design and focus group.

3.2 Study Setting

The study was conducted in Kasama urban and peri-urban areas. Kasama is the provincial headquarters for Northern Province. It is about 900,00 kilometres and the furthest provincial headquaters from Lusaka the capital city of Zambia.

Kasama urban and peri-urban fall under Kasama and Lukashya constituencies with a total population of 179,935 (Central Statistical Office, 2000) with a majority of people residing in unplanned settlements.

Northern Province consists of twenty 22 registered organizations providing HIV/AIDS services. Six of them are run by the government and the rest by non-governmental organizations. Ten of these organisations are based in Kasama district and out of which 3 are directly involved in providing home based care services for individuals suffering from AIDS (Report on Home Based Care Programme in Zambia, 2000).

3.3 Study Population

The socio-economic and cultural activities of the Kasama residents are no different from the rest of the people in the Northern Province. Northern is one of the provinces in Zambia whose population is predominantly engaged in agriculture, forestry, and fisheries industry (67%) followed by trading (11%) and social and personal services (9%), (LCMS 1996). These income-generating activities range from public and private to subsistence farming. It is also the 3rd province (57%) in Zambia, from Southern (72%) and Luapula (66%), in the consumption of own produced food. The main food crops produced in the province are cassava, beans and groundnuts. (CSO, 1996). The adult illiteracy level of Northern Province is 46%, which is slightly above the estimated (40%) national one. It should be noted that a well-educated population is one of the main assets a country can have in order to increase productivity and promote development. The Kasama residents are Bemba by tribe and few other tribes live there.

3.4 Sampling Procedure and sample size

The study population consisted of 187 households, with individuals suffering from HIV/AIDS, under home-based care programme in Kasama urban and peri-urban. The list of patients was obtained from Kasama District Health Office the overseer of the home-based care programmes in the District.

The sampling size of 106 caretakers was arrived at using the formula:

$$\frac{n}{1-\left(\frac{n}{\text{Population}}\right)} = \quad n = \frac{z^2 pq}{d^2}$$

The EPI info version 6 programme was used to calculate the sample size upon considering a confidence level of 95% and expected frequency of 80%; worst acceptable 75% based on 187 HIV/AIDS patients.

A simple random technique, with the use of a table of numbers consisting three digits each number, was used to draw the 106 families with HIV/AIDS patients.

Minimum age entry was determined by the fact that, due to negative impact of HIV/AIDS, some children were heading households, also some girls already got into marriage by that age. If the chosen household did not satisfy the inclusion criteria the next household on the list was picked.

It also involved 10 potential caregivers who were picked for focus group discussion. These constituted the nearest households each to the family living with individuals suffering from HIV/AIDS.

3.5 Data Collection Techniques

The respondents were interviewed using an in-depth structured (closed and open ended) questionnaire. A focus group discussion was held with ten potential caretakers using guidelines for focus group discussion.

3.6 Ethical Consideration

Permission to conduct the study was sought from the Research Ethics Committee of the University of Zambia, Directorate of Research and Graduate Studies, Northern Province HIV/AIDS Network Co-ordinator and Administration of Kasama District Health Management Team.

Written consent was obtained from the respondents. An explanation of how the respondents had been selected in the sample, purpose and nature of study and how the findings would be utilized was made available to the respondents. The subjects were assured of confidentiality and anonymity of data as neither their names nor home address was to be included in the study.

3.7 Pilot Study

Pre-test of the interview schedule and guideline for focus group discussion was done on caretakers and potential caretakers of whom were not included during the final data collection period. Modifications were done to the questionnaire involved the inclusion of questions on marital status and diagnosis of HIV/AIDS patients (questions 10 and 13). Also elimination of some ambiguity on questions 5 and 7 were done as well.

3.8 Data Processing and Analysis

Statistical analysis was conducted using Epi-info 6 software. Yate's corrected chi-square was used only where an uncorrected Pearson's chi-square test for analysis of categorical variables was not applicable, eg cell frequency less than 5. A significance level of 0.05 was used. Results have been presented in graphs and frequency tables. Percentages were not calculated for sample categories less than 30.

3.9 Limitations of the Study

Sensitivity of some of the questions regarding poverty and HIV/AIDS could have affected the interview process limiting the quality and quantity of information obtained even though confidentiality and anonymity were assured.

Inadequate research funds, for transport, which made it difficult in tracing respondents since their homes, were quite spaced.

CHAPTER FOUR

4.0 FINDINGS

SECTION 1

4.1 DEMOGRAPHIC DATA

A. RESPONDENTS

A sample of 106 family caregivers, comprising 85 (80.2%) females and 21 males, was interviewed. Out of these respondents 50 (47.2%) were drawn from peri-urban area and the rest were from urban. They were all Christians. The median age of the caregivers was 36 years: (Q_1 = 26, Q_3 =43). Of the total caregivers interviewed, only 7.5% attained higher/college education whilst the majority (39.5%) obtained primary education and 21.7% never went to school: (Table 1).

Table 1: EDUCATIONAL LEVEL of CAREGIVERS

	CAREGIVERS	**FREQUENCY**	**PERCENT**
1.	Non	23	21.7
2.	Primary education	42	39.6
3.	Secondary	33	31.1
4.	Higher/college	8	7.5
	TOTAL	**106**	**100**

Table 2 indicates that only 12.3% of the caregivers were in employment.

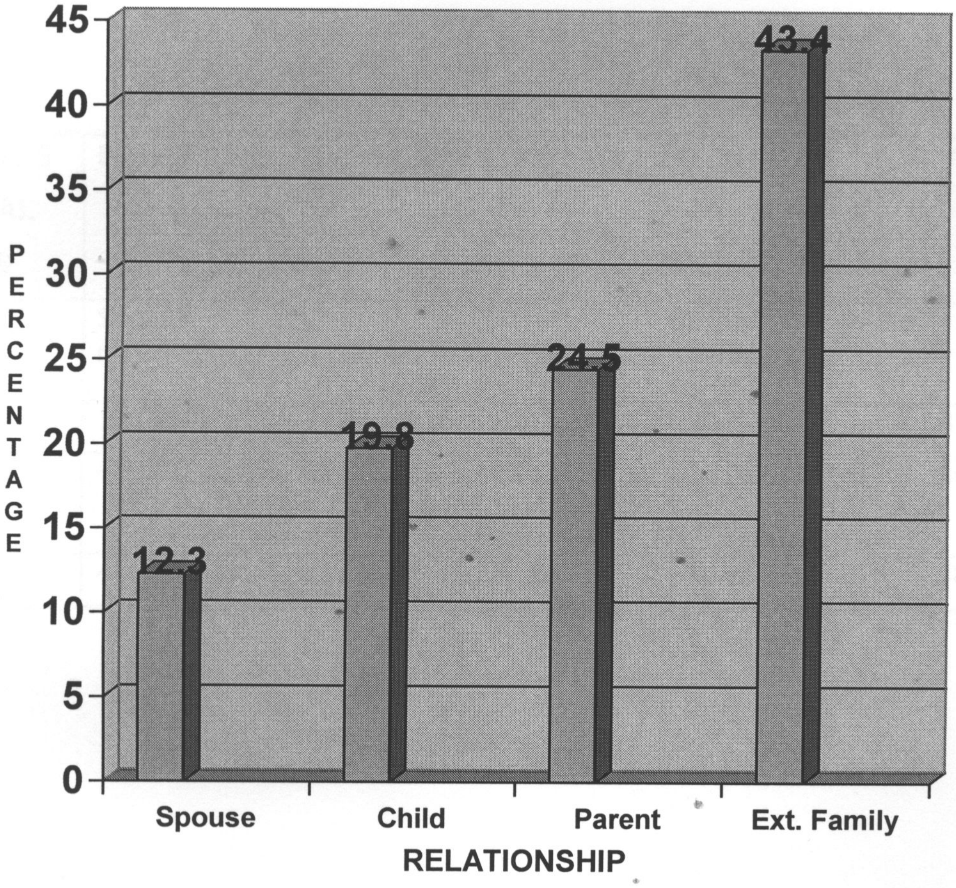
Most (48.1%) respondents were either marketeers or peasant farmers, followed by 31.1% who were not engaged in any income generating activity.

Table 2: SOURCE OF INCOME OF THE CAREGIVERS

	SOURCE	FREQUENCY	PERCENT
1.	Employment	13	12.3
2.	Marketer/farmer	51	48.1
3.	Others	9	8.5
4.	Non	33	31.1
	TOTAL	**106**	**100**

Extended family members 46(43.4%) who included sisters, brothers, aunt, uncle and grand parents, took the highest proportion of home based caregivers followed by parents 26 (24.5%) (Figure 1)

FIGURE 1: DISTRIBUTION OF CAREGIVERS



The extended members of their families looked after the majority (47.8%) of the married HIV/AIDS patients. Meanwhile children cared for most of the (40%) widow / widowers as shown in table 3.

Table 3: MARITAL STATUS OF HIV/AIDS INDIVIDUALS IN RELATION TO CAREGIVER

PATIENT'S MARITAL STATUS	**RELATIONSHIP OF CAREGIVER TO PATIENT**				**TOTAL**
	Spouse n (%)	Child n (%)	Parent n (%)	Extended family member n (%)	
Married	13 (30.9)	3 (7.1)	6 (14.3)	20 (47.6)	42 (100)
Single/ divorced	-	6 (17.6)	12 (35.3)	16 (47.1)	34 (100)
Widower	-	12 (40%)	8 (26.7)	10 (33.3)	30 (100)

No association was observed between residence of families living with HIV/AIDS patient and family size (p=0. 187). Most families either in urban (51.8%) or peri-urban (48.0%) comprised 6 to 10 family members (Table 4).

TABLE 4: RESIDENCE OF FAMILIES LIVING WITH HIV/AIDS PATIENTS IN RELATION TO FAMILY SIZE

RESIDENCE	**FAMILY**			**TOTAL**
	(1-5)	(6-10)	(11and above)	
Urban	7 (12.5%)	29 (51.8%)	10 (17.9%)	56 (100)
Peri-urban	20 (40.0%)	24 (48.0)	6 (12)	50 (100)

Table 5 shows no association between relationship of caregiver to HIV/AIDS patient and knowledge of patient's diagnosis: (p=0.992). Out of the 106 caregivers only 38 knew true diagnosis of the patients under their care (Table 5)

TABLE 5: PERCEIVED DIAGNOSIS OF HIV/AIDS PATIENTS BY THEIR CAREGIVERS

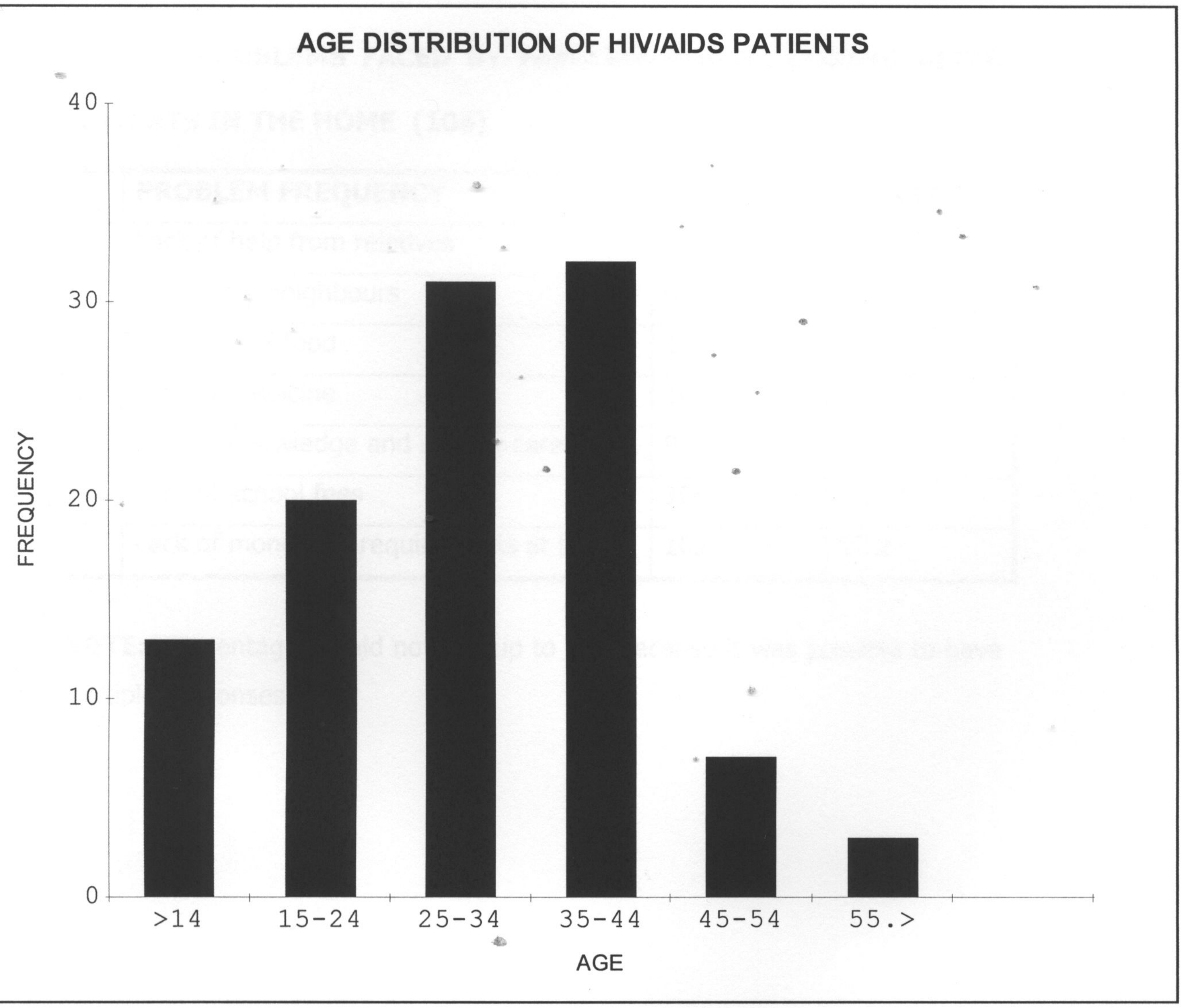
RELATIONSHIP OF CAREGIVER	**PERCIEVED DIAGNOSIS OF PATIENT**				
	Diarrhoea * n (%)	Tuberculosis * n (%)	Pneumonia * n (%)	HIV/AIDS n (%)	
Spouse	1	4 (9.8)	1	10 (26.3)	0
Child	2	10 (24.4)	3	6 (15.8)	0
Parent	1	8 (19.5)	4	4 (10.5)	9
Extended family members	1	19 (46.3)	1	18 (47.3)	4
TOTAL	5	41 (100)	9	38 (100)	13

* Percentages not calculated for sample –categories less than 30.

B. HIV/AIDS PATIENTS

Most (59.49%) HIV/AIDS patients were in the age group 25 to 44 years: (Figure 2).

FIGURE 2.



CONSTRAINTS ASSOCIATED WITH HIV/AIDS PATIENT CARE.

Table 6 shows that the majority of families ranging from 91(85%) to 104(98.1%) experienced lack of knowledge and skill for care of HIV/AIDS patients, lack of medicine, food and money for school fees and other requirements at home.

Table 6: PROBLEMS FACED BY FAMILIES WHEN LOOKING AFTER PATIENTS IN THE HOME (106)

	PROBLEM FREQUENCY		PERCENT
1.	Lack of help from relatives	41	38.7
2.	Unfriendly neighbours	44	41.5
3.	Shortage of food	104	98.1
4.	Lack of medicine	103	97.2
5.	Lack of knowledge and skill for care	91	85.8
6.	Lack of school fees	104	98.1
7.	Lack of money for requirements at home	103	97.2

NOTE: percentages could not add up to 100 because it was possible to have multiple responses.

Most (50.9%) families sought assistance from relatives as a way of coping with the problems associated with the care of HIV/AIDS patients at home. Sell of family assets (38.7%) and depending on charity (14.2%) were also some of the ways families used to cope with the burdens of care as shown in the Table 7.

TABLE 7: WAYS OF COPING WITH PROBLEMS OF CARE BY FAMILIES LIVING WITH HIV/AIDS PATIENTS (n =106)

WAYS OF COPING WITH PROBLEMS OF CARE	**RESPONSE**	
	Yes	**No**
Sell family asses	41 (38.7%)	65 (61.3%)
Seeking assistance from relatives	54 (50.9%)	52 (49.1%)
Depending on charity	15 (14.2%)	91 (85.8%)
Others	12 (11.3%)	94 (88.7%)

NOTE: Possible to have had more than one response

Table 8 indicates that there was no association observed between HIV/AIDS counseling of caregivers and knowledge of care of patients: (p=0.717).

TABLE 8: HIV/AIDS COUNSELLING IN RELATION TO KNOWLEDGE OF CARE FOR HIV/AIDS PATIENTS

HIV/AIDS COUNSELL	**KNOWLEDGE OF CARE**		**TOTAL**
	Yes	**No**	
Yes	6	32	38
No	9	59	68
TOTAL	**15**	**91**	**106**

FEAR OF HIV INFECTION TRANSMISSION

Most 59 (55.7%) caregivers believed that living with individuals suffering from HIV/AIDS pose moderate to high risk of infection transmission to other family members (Table 9).

TABLE 9: CAREGIVERS'PERCEPTION OF RISK OF INFECTION BY LIVING WITH HIV/AIDS PATEINTS

	RISK OF INFECTION	**NUMBER**	**PERCENT**
1.	No risk of infection	17	16.0
2.	Small risk of infection	30	28.3
3.	Moderate risk of infection	30	28.3
4.	Great risk of infection	29	27.4
	TOTAL	**106**	**100.0**

Table 10 shows that of the 29 caregivers who believed that living with HIV/AIDS patients poses great risk of contracting infection by other family members, most of them (13) attributed the risk to lack of knowledge about the disease.

TABLE 10: RESPONDENTS' REASONS FOR CONSIDERTING LIVING WITH HIV/AIDS INDIVIDUALS A GREAT RISK OF INFECTION TRANSMISSION (n=29)

	REASON FOR GREAT RISK INFECTION	FREQUENCY
1.	Lack of protective materials	8
2.	Practicing unsafe sex with known or suspected HIV/AIDS spouse	2
3.	Lack of knowledge about the disease	13
4.	Sharing a room with HIV/AIDS individual	1
5.	Use of same utensils with HIV/AIDS individuals	2
6.	Coughing	2
7.	Mother child transmission (pregnancy and breast feeding)	1

Majority (35.8%) caregivers did nothing at all to avoid contracting HIV infection from the patient they lived with, whilst some used room isolation of patient (21.7%), avoiding sharing of sharp instruments like razor blades and needles (19.8%) and some married couples practiced safe sex (17.0%) (Table 11).

TABLE 11: WAYS OF PREVENTING SPREAD OF HIV INFECTION BY FAMILIES LIVING WITH HIV/AIDS PATIENTS (n=106)

	WAYS OF INFECTION PREVENTON	**FRQUENCY**	**PERCENT**
1.	Isolation of patient by providing own bedroom	23	(21.7)
2.	Avoiding sharing of sharp instruments	21	(19.8)
3.	Not using same kitchen utensils	17	(16.0)
4.	Avoid contact with patient's body secretions	11	(10.4
5.	Practicing safe sex	18	(17.0)
6.	Covering mouth on coughing	19	(17.9)
7.	Nothing at all/leave in God's h. ands	38	(35.8)
8.	Others	14	(13.2)

NOTE: Respondents gave multiple responses that is why the percentages could not add up to 100.

SUPPORT FOR FAMILIES LIVING WITH INDIVIDUALS SUFFERING FROM HIV/AIDS

Out of 106 caregivers, the majority 40 (37.7%) did not receive any kind of support. Among those who received support most of them received materials (53.0%) and counselling (57.8%) from community support systems (Table 12).

TABLE 12: KIND OF SUPPORT GIVEN TO FAMILIES LIVING WITH HIV/AIDS INDIVIDUALS (n=66)

	KIND OF SUPPORT	FREQUENCY	PERCENTAGE
1.	Money	13	19.7
2.	Materials	35	53.0
3.	Counselling	38	57.6
4.	Labour	18	27.3

NOTE: Possible to have had more than one response.

RESPONDENTS' SUGGESTIONS

Table 13 shows that most caregivers suggested food (91.5%) and drugs (87.8%) as the kind of support required for families with HIV/AIDS in order to cope.

TABLE 13: RESPONDENTS' SUGGESTIONS ON KIND OF SUPPORT TO ENABLE FAMILIES LIVING WITH HIV/AIDS INDIVIDUALS TO COPE: (n=106)

	KIND OF SUPPORT	FREQUENCY	PERCENTAGE
1.	Provision of free food	97	91.5
2.	Provision of drugs	91	85.8
3.	Money for income generating projects	19	17.9
4.	School fees and money for school uniforms	23	21.7
5.	Transport for taking patient to and from health facility	18	16.9
6.	Counselling services	21	19.8
7.	Maintain confidentiality	7	6.6
8.	Keep patient in hospital	12	11.3

NOTE: Percentages were not adding up to 100% because it was possible to have had multiple responses.

4.2 SECTION 2

FOCUS GROUP DISCUSSION

1. PROBLEMS OF HOME-BASED CARE FACED BY FAMILIES WITH HIV/AIDS PATIENTS

- **Risk of contracting HIV infection**

  The focus group members pointed out that most of the home-based caregivers for HIV/AIDS patients were at risk of HIV infection since they did not have gloves to use when bathing, turning patients in bed and cleaning those who messed themselves up in bed.

- **Lack of Food**

  It was revealed that HIV/AIDS patients needed adequate and nutritious food, which the majority of the families could not afford to provide. Some of the families were said to have no food to feed other family members.

- **Poverty**

  They lamented that poverty was the greatest cause of much of the suffering most families were going through. Basic home requirements such as mealie meal, relish, clothes were said to be difficult to come by.

- **Irritable Patient**

  HIV/AIDS patients, especially in their advanced stage of illness, were difficult to look after, usually wanted things done in their own way.

- Some patients would even leave usual residence and be cared for by other relatives.

- Others believed there was always a cause for such kind of behaviour among others included not being attended to on time, 'non genuine' visits, stigma attached to HIV/AIDS, life long and life threatening illness.

The focus group believed and suggested that the community should be supportive, sympathetic, loving and caring to the caregivers.

- **Burnout**

- It was agreed that burnout arose from prolonged provision of care, though initially it was attributed to patients being irritable.
- Suggested interventions to the burnout problem included:

- Cooperation and coordination of care within family circles.

- Providing basic requirements such as food, gloves and soap to the families living with HIV/AIDS patients by organizations running Home Based Care Programmes to enable families cope with the care.

- **Transport**

- Families with HIV/AIDS patients usually experienced problems in transporting their patients to health facilities.
- Bicycles and wheelbarrows were mentioned as the common means of transport to a health facility for HIV/AIDS patient.

2. COMMUNITY ASSISTANCE TO FAMILIES LIVING WITH HIV/AIDS PATIENTS

The Focus Group members were aware of the existence of some organizations in the area that were involved in HIV/AIDS. Unfortunately most of them did not know the assistance they rendered to the afflicted families apart from creating community awareness about HIV/AIDS and the care of orphans.

3. ATTITUDE OF FAMILY MEMBERS TOWARDS THEIR HIV/AIDS INDIVIDUALS

Some observations made by the Focus Group were that:

- Some caregivers sacrificed their lives by handling infective materials without any kind of protection in the name of showing love and care.
- Some families attributed the cause of illness of their relatives to witchcraft.
- Majority of families no longer neglected the care of patients on the basis of having contracted a preventable disease.
- In certain homes patients did not share kitchen utensils with the rest of the family members while in other homes, room isolation was used as a coping strategy for spread of HIV infection.

4. ATTITUDE OF COMMUNITY MEMBERS TOWARDS THE FAMILIES LIVING WITH HIV/AIDS PATIENTS

- Focus group pointed out that people were more sympathetic to the families living with HIV /AIDS individuals than they used to be in the past since it is now a common disease and poses a heavy burden of care.
- Visits to the sick within neighbourhoods occurred except those patients were selective as to who visited them.

- Some members indicated that community members that provided assistance to the sick were usually church organisations to which the patient or family belonged.

5. SUGGESTIONS

Suggestions made by the Focus Group on how to make families living with individuals suffering from HIV/AIDS cope with their care included:

- All family members should be counselled and informed about the HIV status of the patient living with them.
- Keep the very chronically ill patients in hospital until death to minimise psychological stress on family members and to give respect for human life.
- Health care providers should visit patients so that they see for themselves the problems experienced at home.
- Provide free antiretroviral drugs since most of the families are too poor to buy them.

CHAPTER FIVE

5.0 DISCUSSION OF FINDINGS

5.1 DEMOGRAPHIC CHARACTERISTICS

The study findings revealed that there were more female than male among home-based care providers with a ratio of about 4 female: 1 male. This is consistent with the observation made by Lepage, et al (1996) that women take on a double burden of production and care provision in households with HIV/AIDS patients. In certain instances women's labour is reallocated from income generating outside the home to caring of children. This practise could be attributed to cultural norms that dictate women to look after the sick while the men take up the responsibility only when the prevailing situation forces them.

The majority of the caregivers were aged between 35 years and 44 years, compared to HIV/AIDS patients under their care whose average age of illness was between 25 and 44 years. This means that the caregivers cared for individuals who were either younger than themselves or age mates. Moreover these groups, of caregivers and HIV/AIDS patients, fall mainly within the most economically productive and sexually active age bracket (15–49 years). For caregivers it means that their concentration and participation in productive activities is reduced since they have to spend most of their time caring for the sick. Morbidity and mortality in this segment of the population constitute not only a national economic burden but have significant family consequences since most people, in this age group, are raising young children.

Most (39.6%) respondents attained primary education only, and 21.7% never went to school (Table 1). This is suggestive of a low literacy level in the study population. It should be noted that a well-educated population is one of the main assets a country can have in order to increase productivity and promote development.

Of the 106 respondents interviewed only 12.3% were employed and majority of them were either marketeers/peasant farmers (48.1%) while others were not employed (31.1%). It is not uncommon for those who drop out from school at primary level or have no education at all to find it difficult to secure a job. The individuals with no or low level of education lack necessary qualifications for most jobs, let alone well paying ones. It is assumed that as a result, they may be a liability to the surrounding community or nation. Therefore it becomes more deplorable for one to assume a role of home care provider without a stable source of income. According to Topouzis and Guerny (1999) the ability to cope with the implications of HIV/AIDS impact mainly depends on the family's economic and socio-cultural conditions and status.

Ching'ambo et al (1998) reported that poverty increases people's risk environment for acquiring the HIV infections, since they may resort to prostitution as a way of raising money to earn a living. HIV/AIDS on the other hand exacerbates poverty; for the families tend to spend the available resources on special diet, transport and medicines for the patient.

Almost 50% of the caregivers were from extended family members (sisters, brothers, aunt, uncle and grandparents) who provided care for most of the married HIV/AIDS patients. This scenario is suggestive that some families altered their household composition as a response to the HIV/AIDS impact. The alteration of households is either the HIV/AIDS patient left usual residence or if the prospective caregiver shifted to the home of the patient. This was also revealed by the focus group discussion that the HIV/AIDS victim quite often leaves usual residence to seek protection and love elsewhere. Few relatives shift to the homes of the sick to provide care. Meanwhile the study findings on "sustainable Agriculture/Rural Development and Vulnerability to the AIDS Epidemic" in Uganda indicated that distress migration is more prevalent than taping of obligations from extended family or community members (Topouzis and Guerny 1999).

Distress migration if it involves married HIV/AIDS patients definitely may lead to separation or divorce which may cause more psychological stress to the family members especially the children.

- **Stigma**

The focus group discussion indicated that HIV/AIDS patients usually wanted things done in their own way. For example most patients in the advanced stage of AIDS did not want to be visited by neighbours and friends or generally because selective as to who visited friends or generally became selective as to who visited them. However, other members of the discussion group who stated that people usually visited to satisfy their curiosity about the extent of the illness and not help the sick, justified the behaviour portrayed by patients. Further more they were of the view that families with individuals suffering from HIV/AIDS needed a lot of support, sympathy, empathy, and love. Their feelings were attributed to the fact that the HIV/AIDS patients were suffering from a life long and life threatening illness whose burden is not easy to carry with limited resources.

Moreover HIV/AIDS patients were difficult to look after because they harboured feelings of rejection and blame by society, due to stigma attached to the disease. The views of the focus group were quite contrary to the findings obtained in India (WHO, 1999), Ghana (Anarif, 1999) and Central African Republic (World Bank, 1997) that people infected with HIV somehow deserve their fate, deserve no care and should be killed. However studies conducted in Kaigera-Tanzania (Kalijage, 1999) and Rakai districts in Uganda (Ankara et al, 1996), showed similar observations that people were generally more sympathetic to persons with AIDS and it is less a disease of shame than it used to be.

- **Fear of HIV Infection Transmission**

Most caregivers (55.7%) felt that they were at risk of contracting the HIV infection. Some of the eminent reasons for fear of infection transmission were lack of knowledge about the disease and lack of protective materials. Although some respondents suggested that they needed gloves to avoid contact body fluids especially reasons for fear of infection transmission were lack of knowledge about the disease and lack of protective materials. Millstein et al (1997) also observed that individuals who either do not perceive themselves at risk or deny risks of illness are less likely to adopt health-protective behaviour. Wrong perception, due to lack of knowledge, about HIV transmission was also demonstrated by majority of caregivers who used room isolation of patient (21.7%) and avoided using same kitchen utensils (16.0%) with HIV/AIDS patients for prevention of infection transmission. On the contrary some families (35.7%) did nothing at all for prevention of HIV infection transmission from the patient they lived with. Some of these caregivers indicated that God would protect them from contracting the infection, while others lacked protective materials.

Although some respondents suggested that they needed gloves to avoid contact with body fluids especially HIV/AIDS undoubtedly play a catalytic role in household food security for it is uncommon in these households to have an increase in household expenditures due to medical treatment, transport, special foods for patient. Above all an increase in the dependency ratio due to the large family size (majority being 6-10) relying on a smaller number of productive family members.

The findings were consistent with the postulation made by the Southern Africa AIDS Information Dissemination Services (SAFAIDS) that a food crisis could erupt in sub-Saharan Africa within the next 20 years as the productive

- **Medicines**

Ninety three percent of the respondents stated that their patients lacked medicines for treatment of their illness. Surprisingly, medicines for treatment of tuberculosis were among the antiretroviral (ARVs) drugs and immune boosters, which were of major concern by families living with individuals suffering from HIV/AIDS.

The cost of ARVs, which ranges from US$100 to US1100 for treating an AIDS patient from the time of diagnosis until death in Africa is obviously not affordable by most Zambians (World Bank, 1997). In recognition of this now Zambia has ARV policy on drug distribution, purchase, and dispensing of ARVs in public health facilities throughout the country which may enable patients access them.

access them.

- **Knowledge of Care for HIV/AIDS Patients**

  It is generally known that knowledge is "power" for it enables individuals make informed and wise decisions. This belief equally applies in the care of HIV/AIDS patients. On the contrary the study findings show no association showed no association between counselling of HIV/AIDS care providers and their knowledge of care. This could be attributed to the fact that more than half of the caregiver (64.2%) did not know the HIV status of patients under their care. Most of them mentioned tuberculosis (38.6%) as the diagnosis of their patients. This situation could have been due to non-sharing of information/diagnoses not only within family circles but also between health care staff and home-caregivers. This was also compounded by the non-involvement of most of the care providers in HIV/AIDS counseling since the majority (64.2%) care providers did not receive HIV counseling services. This points to the need for provision of HIV/AIDS counseling not only to the patients but to the significant others involved in the care of these patients as well.

- **Burnout Syndrome**

  The focus group believed and suggested that the burnout experienced by caregivers arise from prolonged provision of patient care, of which causes psychological stress, neglect and or rejection of patients. As a mitigation intervention to this effect they registered that the carers in the management of HIV/AIDS patients should be cared for.

- **Transport**

Lack of transport was a major problem experienced by caregivers. The focus group members observed that when need arose to take patient to and / or from health care facility the caregiver would be found without money. They further registered that in some cases a wheelbarrow would be used to transport patients, while other patients would be carried on the back of caregivers.

Support for Families Living With Individuals Suffering from HIV/AIDS

The common source of support for most (50.9%) families living with HIV/AIDS patients was relatives/extended family members. The families also sold their assets (38.7%) such as household property, livestock to cope with the burden of care. The charitable organisations (14.2%) whether non-Governmental Organisations (NGO's) or churches contributed to the care of the patients. The Catholic Church, Kasama Centre for Children in Crisis and Northern Province Health Education Unit were some of the community support structures involved in the support system.

However limited coverage in terms of support to patients was a source of worry and concern since 40 caregivers stated having never received any kind of support from community based structures.

The study findings also demonstrated that among those who received support most of them got materials (53%) and counselling (57.8%). The materials provided included foodstuffs, medicines, clothes for children, gloves and on rare occasions agricultural inputs such as seeds and fertilizer.

According to Nkandu Luo, (2001, personal communication), it is more important to initiate income-generating activities for HIV/AIDS patients than provide handouts.

CHAPTER SIX

6.0 CONCLUSION AND RECOMMENDATIONS

6.1 CONCLUSION

Most of the families living with HIV/AIDS patients lacked employment, income earning activities, knowledge of disease, skill of care, food and medicines which enable families cope with care of their patients. Therefore poverty affected the experience of HIV/AIDS patients both in the progression of the disease, since they lacked the necessary nutrition and medications/ARVs, and quality of care received.

6.2 RECOMMENDATIONS

1. There is need to improve the household food security and nutrition of the families living with individuals suffering from HIV/AIDS in Kasama urban and periurban.

2. The general improvement in the socioeconomic conditions of the families with HIV/AIDS patients can improve access to the antiretroviral drugs, which are necessary to improve their health and life span.

3. A study should be conducted to assess factors hindering access to tuberculosis drugs in the area since most caregivers stated that their HIV/AIDS patients with tuberculosis were not on treatment.

4. There is need to intensify HIV/AIDS counselling involving home care providers and not only HIV/AIDS patients, and the dissemination of information about the spread of the disease for increased community awareness and to decrease the level of stigma.

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THE UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE

DEPARTMENT OF COMMUNITY MEDICINE

INTERVIEW SCHEDULE FOR COLLECTION OF DATA ON: COPING STRATEGIES OF FAMILIES LIVING WITH INDIVIDUALS SUFFERING FROM HIV/AIDS

HOUSEHOLD NUMBER……………………………………………………

INTERVIEW DATE………………………………… ……………………..

INTERVIEWER'S INITIALS……………………………………………………

STRUCTIONS TO RESEARCH ASSISTANTS

Always introduce yourself

Explain the purpose of the study and ask for permission to do the interview.

Let the respondent sign the consent form before you start the interview.

If the respondent is unwilling to take part, do not force him/her.

Do not write the names of the respondents on the interview schedule and assure confidentiality of information.

Write or tick the appropriate response in the space provided.

OCIO-DEMOGRAPHIC DATA

Sex

1. Male ☐
2. Female ☐

Age at last birthday………………………

Level of education

1. Non ☐
2. Primary ☐
3. Secondary ☐
4. Higher ☐

4. Location of household
    1. Urban ☐
    2. Peri-urban ☐

5. What is your relationship to the patient?
    1. Spouse ☐
    2. Child ☐
    3. Parent ☐
    4. Extended family member (relative) ☐

QUESTIONS

6. What is your religion?
    1. Christianity ☐
    2. Hindu ☐
    3. Moslem ☐
    4. Any other, specify.....................................

7. What is your occupation?

....

8. How many people live in this household?
    1. 1 –5 ☐
    2. 2 – 10 ☐
    3. 11 and above ☐

9. How old is the patient?
    1. Under 14 years ☐
    2. 15 to 24 years ☐
    3. 25 to 34 years ☐
    4. 35 to 44 years ☐
    5. 45 to 54 years ☐
    6. 55 to 64 years ☐

10. What is the marital status of the patient?
    1. Married ☐
    2. Single ☐
    3. Divorced /separation ☐
    4. Widowed ☐
    5. Widower ☐

11. How long has the patient been sick? ....

12. For how long has the patient been staying with the family? ....

13. What is the patient's illness? ....

14. What problems do you face connected to the care of the patient at home?

Please tick YES or NO

14.1 Lack of help in caring of the patient from the family/relatives ☐ ☐
14.2 Neighbours are unfriendly to the family ☐ ☐
14.3 Lack of medicines for the patient ☐ ☐
14.4 Lack of money to buy requirements for use on the patient ☐ ☐
14.5 Lack of knowledge and skills to care for the patient ☐ ☐
14.6 Lack of money to pay for children at school ☐ ☐
14.7 Lack of food in the home. ☐ ☐

15. What do you usually do to solve the most common problems that you face while caring for the patient?

1. Sell family assets ☐
2. Getting assistance from extended family ☐
3. Depending on charity (community/church members, organisations, clubs, networks of AIDS) ☐
4. Any other, specify..

16. What kind of assistance connected to the care of patient, does the family get from the main source (s) of support? If any.

1. Money ☐
2. Material ☐
3. Counselling ☐
4. Labour ☐
5. Any other, specify............ ....

17. When was the last time the family got assistance from the major source of support?..

18. Have family members received some counselling services on how to care for the patient?

1. Yes ☐
2. No ☐

19. What are the chances of passing on the infection from the patient to the family members?

1. Small ☐
2. Moderate ☐
3. Great ☐
4. No risk at all ☐

20. If the response to question 19 above is 3 (Great0, why is there a great risk of family members getting the infection from the patient they live with? Give not more than four (4) responses, in order to high risk.

(i) ....

(ii) ....

(iii) ....

(iv) ....

21. What do the family members do to avoid getting, the disease from the patient they live with? Mention not more than four (4) responses in order of priority.

(i) ....

(ii) ....

(iii) ....

(iv) ....

22. Do you think you are coping with the care and support being rendered to the patient living with you?

1. Yes ☐
2. No ☐
3. No idea ☐

23. If the response is no to the above question, what should be done to enable the family cope with the problems of caring for chronically ill patients? Give not more than four (4) responses according to priority.

(i) ....

(ii) ....

(iii) ....

(iv) ....

Thank you for sparing your time for the interview.

****

APPENDIX B

OBJECTIVES OF THE FOCUS GROUP DISCUSSION

1. To establish their views on the problems faced by families when looking after HIV/AIDS patients in their homes.
2. To determine whether families living with HIV/AIDS patients get any assistance from the community in the care of their patients.
3. To determine their views about the attitude of family members towards the HIV/AIDS patients they live with.
4. To establish the attitude of community members towards the families living with HIV/AIDS patients and the patient in particular.
5. To obtain suggestions for the improvement of the home-based care programme.

GUIDELILNE FOR FOCUS GROUP DISCUSSION

INSTRUCTIONS TO RESEARCH ASSISTANTS

- Introduce the session, yourself and recorder and the participants.
- Encourage them to discuss and be involved.

ITEMS FOR DISCUSSION

1. Major problems faced by family while caring for the patient.
    - Food
    - Drugs
    - Transport
    - School fees

2. Assistance from community support systems

- Not forthcoming
- Rarely available
- Available
- Stigmatization

3. Kind of assistance provided, if any.

- Monetary
- Labour
- Material

4. Family support (support within the family)

- Support of funding/resources
- Motivation
- Daily problems/solutions
- Stigmatization

5. General comments on home care services

- Successful
- Shortcomings
- Constraints

6. Suggestions to improve the care and support of the patient at home.

- Introduce support projects
- Provide handouts
- Involvement of extended family

University of Zambia,
School of Medicine,
Department of Community Medicine,
P O Box 50110,
LUSAKA.

3rd January 2002

To: ……………………………………………
……………………………………………
……………………………………………

Dear ……………………………………………

RE: PERMISSION TO CARRY OUT A STUDY ON COPING STRATEGIES OF FAMILIES LIVING WITH INDIVIDUALS SUFFERING FROM HIV/AIDS IN KASAMA URBAN AND PERI-URBAN

I am a post graduate student pursuing master of Public Health at the University of Zambia asking for permission to conduct a research in Kasama Urban and peri-urban. For my dissertation, I have chosen to look at the coping strategies of families living with individuals with HIV/AIDS.

This will involve assessment of the resources available in the home for the care of the chronically ill individual and the support received from the various organisations or individuals including family members, in the community.

The research will entail interviewing the primary caregiver that is the person who looks after the patient in the home. Also a focus group discussion with potential caregiver, each drawn from the nearest household to the family with a chronically ill patient, will be conducted.

Confidentiality will be maintained and informed consent will be obtained from all respondents. The research Ethics committee has already approved the study as evidenced by the letter of approval attached herewith. If permission is granted, I hope to carry out the study between January and February 2002. Should permission be granted, I would request to be introduced to the caregivers through your home care focal person(s).

Thanking you in anticipation.

Yours faithfully,

LSON MUULU

Dr S. Siziya – MPH Co-ordinator
Research Supervisor
Chairman Research Ethics Committee

CONSET TO PARTICIPATE

I have read been told about the above statements and have understood the information given. I am willing to participate in the study.

Signature or thumb print:-----------------------------

Date: --

If there are any queries, please contact me. My address is:

Muulu Elson
School of Medicine
Department of Community Medicine
P.O. Box 50110
LUSAKA

All communications should be addressed
o the District Director and not
o individuals
elephone: 221654
elefax: 221096

In reply please quote
No.

REPUBLIC OF ZAMBIA

MINISTRY OF HEALTH

OFFICE OF THE DISTRICT DIRECTOR OF HEALTH
KASAMA DISTRICT HEALTH BOARD
P.O. BOX 410156
KASAMA

Mr. Elson Muulu
University of Zambia.
School of Medicine.
Department of Community Medicine.
P.O. Box 50110.
Lusaka.

Dear Sir,

Re: Permission to carry out a study on coping strategies of families living with individuals suffering from HIV/AIDS in Kasama urban and peri-urban.

We herby inform you that permission has been granted for you to carry out the above-mentioned study. You will be introduced to the community based Organisation dealing with home based care by the district HIV/AIDS coordinator.

We wish success,

Thank you,

Dr Felix Silwimba.
District Director of Health.

c.c. Mr. Mate. District HIV/AIDS coordinator.

NORTHERN PROVINCE HEALTH EDUCATION PROJECT,

Each one *Teach one*

The Zambian Approach

PO BOX 410026,
KASAMA.

4th January, 2002.

Mr. Elson Muulu,
University of Zambia,
School of Medicine,
Department of Community Medicine,
PO BOX 50110,
LUSAKA.

RE: PERMISSION TO CARRY OUT A STUDY ON COPING STRATEGIES OF FAMILIES LIVING WITH INDIVIDUALS SUFFERING FROM HIV/AIDS IN KASAMA URBAN AND PERI-URBAN

With reference made to your letter dated 3rd January, 2002, concerning the above mentioned study, I wish to inform you that as a project, we have granted you permission to carry out the study in our operational areas with groups involved in Home care of people living with HIV/AIDS and their families.

Please report to the our AIDS information Centre on Tuesday, 8th January, 2002 where arrangements will be made for you to meet with our focal point persons.

We wish you all the best with your study.

Godfredah C. Mugala
Project Co-ordinator.

THE UNIVERSITY OF ZAMBIA
RESEARCH ETHICS COMMITTEE

Telephone: 252641
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-250753

Dean's Office
P.O. Box 50110
Lusaka, Zambia

26th September 2001

Mr E Muulu
Department of Community Medicine
UNZA LUSAKA

Dear Mr Muulu

The following research proposal was presented to the Research Ethics Committee on 12th of September 2001 and was approved. Congratulations!

Title of research proposal: **"Coping strategies of families living with individuals suffering from HIV/AIDS in Kasama urban and peri urban".**

Please keep the Committee informed on the progress of your research.

Signed:..............................
PROF R KRISHNA
ACTING CHAIRPERSON RESEARCH ETHICS COMMITTEE