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# HOME CARE FOR PEOPLE WITH AIDS IN LUSAKA

BY

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A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR THE DEGREE OF MASTER OF PUBLIC HEALTH



1997

# DECLARATION

I hereby certify that the work presented in this study, is the result of my individual effort. I also declare that this work presented for the degree of Master of Public Health, has not been presented either wholly or in part for any other degree. All quotations from various sources have been acknowledged.

SIGNED:.....

DATE: 19th March 1998

**CERTIFICATE OF LECTURER RESPONSIBLE**

I am satisfied that this work is the result of students own effort.

SIGNED:.....

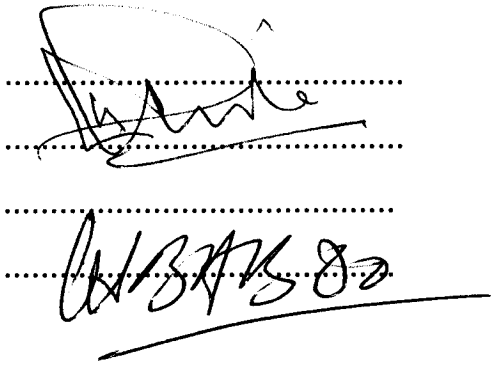
**Dr. K.S.Baboo**

DATE: 23/03/98

## APPROVAL

This dissertation of **Ms. Hilda Vukawaka Kaunda** is approved as fulfilling the requirements for the award of the degree of Master of Public Health by the University of Zambia.

Signature: Date:



# ABSTRACT

HIV/AIDS ia a major problem in urban Lusaka, with many patients now nursed at home in the terminal stages of this illness, (MOH 1992). This is a cross-sectional, descriptive study to assess the symptom management practices, of the Home Based Caregivers for people with AIDS in Lusaka. The study attempted to assess the home remedial practices of careproviders. It also examined the availability of resources for home care and the extent of material and emotional support to the caregivers, from the government, non-governmental organisations, the community and the family members.

A review of the relevant literature was based on the current and projected impact of HIV/AIDS on the government, hospitals and health centres, the infected people and the affected household family members in the homes. In particular, literature explored the experiences of caregivers, while looking after sick people at home.

The target population was all caregivers under Home Care Programme working for a period of six months or more, in the six zones of Lusaka. A semi-structured interview schedule and a checklist, were used to collect data.

The questions aimed to elicit information regarding demographic data of respondents, availability of resources for care in the home, the extent of material and emotional support from the family and the community at large.

The results showed that, over 60 percent of the Home Based Caregivers have problems in coping and caring for people with AIDS. The problem was compounded by the absence of government policy and guidelines on Home Care. The government has endorsed Home Care in its Health Reforms Strategy, but the implementation of Home care has neither been fully implemented nor monitored. There was no funding or allocation, specifically for the home based caregivers. Funding from donors was absorbed in management costs such as salaries and fuel. The caregivers appreciated current services, but expressed several extra needs. Recommendations are made, to various authorities, for consideration.

# ACKNOWLEDGEMENTS

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# CHAPTER 1

## Introduction to the Study and Definitions

## 1.1 **Introduction**

Zambia is a sub-Saharan country with an area of 753,000 square kilometres. According to DHS (1992), the population at the last census done in 1990 was 7.8 million people. The annual population growth was 3.6 percent. Zambia is highly urbanised with 42 percent of the population living in towns and cities. According to the 1996 Countrywide Survey on Poverty by Mr S. Sachika, former Secretary to the Cabinet, 84 percent of Zambians are poor. The World Bank Poverty Assessment (1994), states that, poverty in Zambian is very high. In 1991, 69 percent of all Zambians were living in households where income was insufficient to provide for basic needs. Poor health status was correlated with this poverty, reflected by the diminishing life expectancy of people in Zambia.

The earlier studies on poverty and health, (Demographic and Health Survey 1992) also show that nearly 75 percent of people are below the poverty line. The same report says that on average, each Zambian family has 6.8 people with an average income of K60,000=00 to K100,000=00 per month. The Zambian currency, "Kwacha" has also depreciated over the years. All these combined factors create avicious circle which is a worrying situation for the future of the nation. HIV and AIDS occurs everywhere and problems are compounded in areas where resources are scarce and proper treatment facilities are limited.

Infections such as Tuberculosis and HIV have a disastrous effect on those affected. They are often left helpless, and such asituation it is difficult to make a choice or to set priorities. However proper management of HIV infection and its complications has beenshown to benefit Patients, their families, the health care system and the society at large as evidenced by the success of **Home Based Activities** (NAPCP/WHO 1992). The AIDS pandemic in Zambia is devastating and affects all sectors of society and the economy. From 1992 to 1994, AIDS and the related illnesses, have been the most common cause of deaths in hospitalised adults. The Ministry of Health estimates a cumulative total of 60,000 AIDS cases each year. This is projected to increase from 65,000 to 80,000 by the year 2010, according to MOH/GPA (1994). More than 90 percent of the infected people are expected to go to the health services in search of care, and the greatest burden will fall on Hospitals, where the demand for hospital beds will increase.
While the demand for health services will increase, hospital resources are not expanding. According to the Health Information Unit at the Ministry of Health in Lusaka, in 1984, there were a total of 82 hospitals and 847 health centres, with a total of 21,808 cots and beds. In 1990, the number of hospitals were still 82, but the health centres had increased from 847 to 942.

The total number of beds and cots increased to 24,572, that is by 12.9 percent. This could be interpreted to mean that the number of hospital beds and cots have been increasing by 2.2 percent annually, while the projected demand is 20 percent annually over the next decade. By the year 2010, it is projected that 90 percent of the 25,000 hospital beds will be occupied by people with AIDS (MOH/GPA 1994).

## 1.2 **Background to the study**

As already stated, HIV/AIDS continues to be a major health problem in Zambia today, and is expected to remain so for sometime to come. It is projected that, by the year 1998, there will be about 1.8 million Zambians with HIV infections. The demand for hospital beds will equally increase. In Zambia and other countries in Eastern Africa, up to 60 percent of inpatient admissions on medical wards in major hospital, and 70 percent of Tuberculosis admissions, are HIV positive patients (WHO/GPA 1994). This trend will worsen with increasing numbers of HIV/AIDS cases. There is increasing awareness that, care of people with AIDS requires a broader range of services, that is, medical, social and personal. The long stay of people, with AIDS in hospitals, has resulted in a drain on meagre resour-ces. Standards have declined and sometimes, patients with AIDS are neglected. Home based care is becoming an essential alternative to hospital based care.

One of the advantages of Home Care is that, a patient can be cared for and even die in their own home peacefully rather than in a hospital.

The first person in Zambia to be diagnosed with HIV was in 1985 at the University Teaching Hospital in the Skin Clinic. Prior to this, Verma and Hira (1984) reported 4 cases of Herpes Zoster and Pulmonary Tuberculosis combined. This was an unusual occurence because Herpes Zoster was known to occur in more frequently in an immuno-compromised state and in patients suffering from malignant disorders. From this time more people stiudied this stuation. For example Professor Ann Bailey, of the Deparment of Surgery Tumour Clinic, did some studies on HIV and Karposis Sarcoma. The Government made a delibarate policy to enhance Health Education on HIV/AIDS. To remove the stigma from the infection people who were diagnosed as having the HIV infection came out in the open and assisted in preventive outreach work.
The current Government has even gone a step further by exempting medical fees to patients with sexually transmitted diseases/HIV infection.

The first home care programme was set up at University Teaching Hospital by an American nurse, in 1987. The same programme is currently run by the Family Health Trust, a non-Governmental organisation. In Lusaka Urban, there are two main home based care programmes. The other is run by the Catholic church.

## 1.3 Operational definitions and abbreviations

For the purposes of this study, the following definitions and abbreviations will be used:-

**DEFINITIONS**

Caregivers/Careproviders

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

Chronically ill patient

A person who needs assistance to meet the needs of activities of daily living such as nutrition, hygiene and elimination.

Home Care Unit

A referral unit at the University Teaching Hospital where patients needing home care, are assisted and prepared for home care.

Primary Care Giver

A person who is available to render care day and night in the home, to the chronically ill patient.

Secondary Care Giver

A person who voluntarily assists to care for the chronically ill patient occasionally, but does not reside in the house and is not usually a relation.

Symptom

A visible sign of an underlying disease.

**LIST OF ABBREVIATIONS**

| | | |
|---|---|---|
| AIDS | : | Acquired immune deficiency syndrome |
| FHT | : | Family Health Trust |
| GPA | : | Global Programme on AIDS |
| GRZ | : | Government of the Republic of Zambia |
| HBC | : | Home Based Care |
| HIV | : | Human Immune Deficiency Virus |
| MOH | : | Ministry of Health |
| NACP | : | National AIDS Control Programme |
| NASTLP | : | National AIDS, Sexually Transmitted Disease, Tuberculosis and Leprosy Control Programme |
| NGO | : | Non-Governmental Organisation |
| PWA | : | People/Person with AIDS |
| UTH | : | University Teaching Hospital |
| WHO | : | World Health Organisation |

# CHAPTER 2

## Statement of the problem

## 2.1 **Statement of the problem**

Giving care to people with AIDS in the home, is a demanding task, because, they present themselves with multiple symptoms that need adequate management. The home environment is unsuitable for " hospital-like" care, because it is a place where one lives and finds rest, peace and tranquility. In this era of HIV/AIDS pandemic, affected families have no alternative but to look after their sick relative at home, once they are "prematurely" discharged from the hospital. The patients with AIDS are often discharged with one or more problems still unresolved. The family is expected to assume full responsibility for the caring of the patient and to manage his/her symptoms. The system of discharging patients and referring them to home care, has several problems. The Home based caregiver, and the family members, are at risk of contracting HIV infection if body wastes, from the patient, are mismanaged. The caregiver also needs support, resources, knowledge and skills for symptom control. The understanding of symptom management by home based caregivers, is an important component of overall AIDS control programme. The management of symptoms, particularly those arising from opportunistic infections, is crucial in alleviating suffering and promoting the quality of life.

People with AIDS, being looked after in the home have several other needs. They need to feel loved, accepted, not to be blamed but to be given impartial and compassionate care. The care giver has to be non-judgmental.

Home based care is becoming the alternative to hospital care. According to MOH/WHO/GPA (1994), 'medically unnecessary days' were those days when the patient had "symptomatology" which could have been treated at home.

This study sought to answer how caregivers manage the various symptoms of people with AIDS, in the home environment. The study also hoped to find out what facilities and resources were available to caregivers for symptom management.

The core problem or the dependent variable was, therefore, "Management of medical problems in the home". The independent variables were cost, availability of resources, the referral system, availability of counselling services, basic knowledge about AIDS and the Family and Community Support System. Other variables were stigma, fear of AIDS and knowledge of true diagnosis of AIDS.

## 2.2 **Justification of the study**

So far, no study has addressed this aspect of Home Based Care. The need for this study was one of the recommendations of the survey done in June 1996 by myself, during my two week Field Service Attachment to UTH Home Based Care Unit. The pilot study was carried out on Secondary Home Based Caregivers. This study concerned itself with Primary Caregivers and their management of symptoms in their homes.

# CHAPTER 3

## Review of the relevant literature, aims and objectives and hypothesis

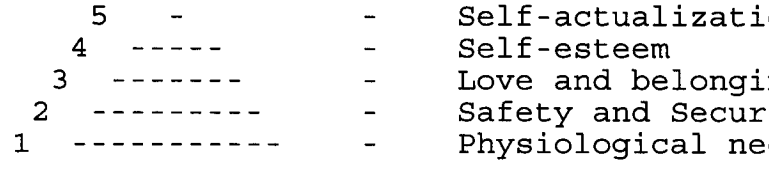
## 3.1 **Literature review**

In Zambia, in the mid 1980s, the non-Governmental sector, began to respond to AIDS' health needs by developing Home Based Care Programmes. In 1986, the Church Medical Association of Zambia (CMAZ), an umbrella organisation of all Mission Hospitals, adopted Home Based Care as a strategy to respond to the AIDS challenge in the country. The UTH Home Care programme, began in October 1987. The demand for Home Care services continued to grow. For example, according to Lungu (1996), the total number of referrals to UTH Home Care Unit in 1994, was 3,368, and in 1995, the annual total increased to 4,887. This showed a 26 percent rise in demand for Home Care Service within that one year. Patients are referred to Home Care for education, counselling and for continuity of supervisory care in homes.

One important identified area of need is SYMPTOM MANAGEMENT. According to GPA/WHO (1989), adequate symptom management is essential in the Home Based Care Programme. The same report outlines common symptoms identified among the patients with HIV infection. They found that 20 percent had a significant psychological component associated with their medical problems. Potter and Perry (1979), state that the process of becoming ill begun with symptoms, which prompts the seeking of medical attention. A person is defined as having optimal health when symptoms have

disappeared. Patients referred to Home Care, are still ill. Home Care is mainly about managing symptoms appropriately and rendering palliative care. According to WHO (1974), "Health is defined as a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity". Persistent symptoms disrupt the normal routine of the family. The patient may fear the consequences of the disease. Some may lose hope and interest in life. If symptoms persist and become severe, the person assumes a "sick role". At this point, the sickness may become a social phenomenon, where the person seeks confirmation from the family or social group that they are sick and should be excused from normal duties, roles and expectations. The people who are referred to Home Care, are usually at this stage of "sick role".

Maslow (1970) designed a hierarchy of human needs. Maslow's hierarchy of needs is a theoretical representation of the levels of basic human needs as demonstrated below:




This hierarchy of human needs has five levels. Maslow's highest priority is given to physiological needs such as air, nutrition, elimination, shelter, rest and maintenance of normal body temperature.

According to this theory, some needs are more basic than others and must be met before one directs attention to the others.

Maslow (1970) further states that, Health is a dynamic state in which an individual adapts to the changes in the internal and external environment, and thus, maintains a state of well-being in all dimensions. Ideally, both needs of the caregivers and those of the patients, should be met to maintain this state of well-being or health. Illness behaviour is heavily influenced by the frequency of symptoms, their tolerance by the patients and others or their management. It is often normal practice to concentrate on the needs of the **patient** in the home and ignore the needs of the **home based caregiver**.

The caregiver has needs too, which need to be met. For example, he/she can have some fears, become intolerant or become depressed. Counselling needs should be met in this case. Mwale and Zulu (1996) reported that, failure to cope adequately with symptoms of people with AIDS in the home, was a major contributory factor to depression among home based caregivers in some Lusaka Urban communities. Mwanza (1994) says that, as her daughter's illness progressed, her body pains also increased. This left her as a care giver helpless.She and her daughter then talked of "assisted suicide", and her mother resolved to help her daughter if she requested it. In fact, the

daughter did not raise the subject again and died naturally. There are psychosocial needs, of both the infected person and the affected family members. Panos (1990) speaks of the isolation and rejection that a caregiver may experience from the family and from friends. The caregiver may fear to tell relatives the true diagnosis of HIV/AIDS for fear of rejection. Illness is never an isolated event because both the patient and family, experience changes in behaviour, in emotions, in family roles, in body image and self-concept. Thus, the referral system should be one that tries to prepare both home based caregivers and the patient, mentally and physically for the change in their family roles. Mwanza (1994), says

> "I had always believed that, in times of stress, a family pulls together, but the exact opposite was the case" (p.11).

She goes on to say that anger, grief, frustration and desperation, culminating in rows and arguments, caused a rift in the family. Macwang'i *et al* (1994), found that, home based caregivers were, highly supported by the family (46%) and church (32%) and Government (11%) during their study on Women and AIDS. McDonell, *et al* (1994), observed that community based initiatives founded in Primary Health Care precepts, are most successful. They further stated that services for home care are often unclear while, current Home Care programmes are often merely extensions of the Health Care System which is not ideal.

The home environment should be taken into consideration and should be one that facilitates caregiving in the home. The caregiver needs resources such as water, heat, light, sanitation, necessary for the activities of daily living. These activities include hygiene, elimination, nutrition, mobility, love and security. Resources available to the family, should be taken into consideration when referring patients to Home Care. Mwanza (1994), from her experience on home care, says that poor people, cannot pay for decent home care. For this reason, home care should not be "rushly" prescribed, because it can be a source of great discomfort and misery to the family.

Communication is an important component of Home Care programmes. The communication system should incorporate the family, the hospital, the donors and the implementing agencies. Information at the time of referral and the expectations of the caregiver from the Home Care Services, are crucial if the Home Based Programme is to work.

## 3.2 **Aims**

The overall aim of the study was to investigate symptom management practices among Home Based Care-givers of people with AIDS.

## 3.3 **Specific objectives**

1. To find out how the referral system prepares home based caregivers for home care.
2. To describe the symptoms or medical problems that the caregivers encounter in the home.
3. To assess symptom home remedial practices in the homes.
4. To determine the human and material support the caregivers receive in their homes.
5. To assess the role of the family and community network in care giving.
6. To report the findings and make recommendations to the relevant organisations.

## 3.4 **Hypothesis**

Home Care programmes are meeting the needs of Homebased Caregivers and their chronically ill relatives despite the absence of Government policy on the operation of Home Care Programmes.

# CHAPTER 4

## Research design and methodology

## 4.1 **Research design**

This was a cross-sectional descriptive study which aimed at collecting and presenting data about Primary Caregivers, and their symptom management practices in the home. The study was designed to quantify the distribution of variables like the socio-economic characteristics of caregivers, the physical characteristics of the home environment, the Caregivers' knowledge on AIDS and their practices, opinions and beliefs.

## 4.2 **The population**

This study, was carried out in the six zones which are run by the Family Health Trust. The six zones which have several compounds under them, are **Kabwata, Kabulonga, Mandevu, Chawama, Kanyama and Matero**. The study was originally planned in the two main homecare programmes in Lusaka. The Catholic Secretarial Homecare Services refused to grant permission for the study to be carried out. All Family Health Trust zones were, instead, selected for the study. The population, from which the sample was taken, were all the Primary Home based Caregivers in the six zones, who had been under Home care super-vision for six months and over.

| ZONE | TOTAL NO. OF CAREGIVERS | NUMBER SELECTED | PERCENTAGE (%) |
|---|---|---|---|
| CHAWAMA | 94 | 11 | 22 |
| KABWATA | 83 | 10 | 20 |
| MANDEVU | 76 | 8 | 16 |
| KANYAMA | 68 | 8 | 16 |
| KABULONGA | 61 | 7 | 14 |
| MATERO | 54 | 6 | 12 |
| TOTAL | **436** | **50** | **100** |

**Data collection**

A semi-structured questionnaire was used to collect data. A checklist was used to check the facilities available in the home to each Caregiver **(Appendix III)**. Interviews were conducted in the homes of those who agreed to participate. The Zone Nurse/Counsellors facilitated the data collection by way of introduction of the researchers to the households. Four Research Assistants were used to collect data.

**Ethical considrerations**

Informed consent was obtained from each respondent, and confidentiality was ensured by conducting the interview in a private room. The checklist of household facilities was completed with the help of the respondents or the Primary Caregivers in each home.

### 4.5 **Questionnaire design**

The questionnaire was designed using open-ended and closed-ended questions (Appendix iii). Space was provided for additional information, opinions or reasons for choice of that particular response.

### 4.6 **Limitation of the study**

There were difficulties in obtaining permission from the organisations that run Home Care Programmes. The Family Health Trust had in June 1996, given permission to conduct a pilot study on the Secondary Caregivers or volunteers. They were hesitant to give permission for the second study to be carried out on the "Primary Caregivers". The reasons given were that they have trained so many Home Based Caregivers for other organisations, so they wanted to get feedback as to the performance of these trained Caregivers. The Home Based Programme Manager at the Catholic Secretariat, refused to give permission saying that such a study would be tantamount to breaching the "Confidence" of their patients. There were time constraints as well. The first letters of permission were sent on 9th December 1996, following approval of the research proposal by the University of Zambia, Research and Ethics Committee. The Family Health Trust could not give permission earlier because The Executive Director was out of office on other duties. Verbal permission by Family Health Trust was therefore

only given in the last week of January 1997. The Catholic Secretariat replied at the same time. Focus group discussions were omitted in view of the fact that only one programme granted permission to carry out this study . The study was originally designed to compare the provision of services between the two programmes.

# CHAPTER 5

## Presentation of results

**RESULTS**

Data was processed by coding and categorising responses obtained from both open-ended and close-ended questions. The EPI-INFO version 6 statistical software was used for some of the analysis of the data. The results are shown in tables below.

**Table 1: SEX DISTRIBUTION OF CAREGIVERS**

| SEX | FREQUENCY | PERCENTAGE (%) |
|---|---|---|
| FEMALE | 43 | 86 |
| MALE | 7 | 14 |
| **TOTAL** | **50** | **100** |

This table shows that the females formed a larger number of Caregivers compared to the males as demonstrated by the above percentages. This can be attributed to cultural norms where women are left to look after the sick. Men only look after the sick, if the situation prevailing forces them to do so.

It is well known that people in the reproductive age group 15-49 years, are more vulnerable to contracting the HIV infection. In the table above, 72 percent fall in the reproductive age group.

**Table 4: RELIGIONS OF CAREGIVERS**

| RELIGION | FREQUENCY | PERCENTAGE (%) |
|---|---|---|
| ROMAN CATHOLIC | 22 | 44 |
| UNITED CHURCH | 7 | 14 |
| NON-CONFORMIST | 5 | 10 |
| DUTCH REFORMED | 4 | 8 |
| SEVENTH-DAY ADVENTIST | 4 | 8 |
| OTHERS | 4 | 8 |
| **TOTAL** | **50** | **100** |

The Roman Catholic Church has the highest percentage of the Caregivers (44%). This may be because it is well spread as it is found in all urban compounds including the shanty compounds. As a result they refer more patients to Home Care than any other denomination. Over 50 percent of the patients referred to Family Health Trust Home Care programme, came from the Catholic church in this study.

**Table 5: EDUCATION LEVELS OF CAREGIVERS**

| EDUCATION LEVEL | FREQUENCY | PERCENTAGE (%) |
|---|---|---|
| PRIMARY | 23 | 46 |
| SECONDARY | 13 | 26 |
| COLLEGE/UNIVERSITY | 6 | 12 |
| NO EDUCATION | 8 | 16 |
| **TOTAL** | **50** | **100** |

Those in the Primary education level are in the majority, because those who drop out from school at primary level ussually find it difficult to get a job because they are young and they lack qualifications for most jobs. It is assumed that as a result, they may resort to crime and prostitution, to earn money, thereby being at risk of contracting HIV infection.

**Table 6: RELATIONSHIP OF CAREGIVERS TO PATIENTS**

| RELATIONSHIP | FREQUENCY | PERCENTAGE (%) |
|---|---|---|
| MOTHER | 16 | 32 |
| SELFCARING | 13 | 26 |
| SISTER | 6 | 12 |
| WIFE | 5 | 10 |
| OTHER | 10 | 20 |
| **TOTAL** | **50** | **100** |

This table shows the relationship of the primary Caregiver to the patients. There is gender imbalance in that 27 (54%) are females.

This point was shown in table one as well where we had 43 female Caregivers as opposed to 7 males. Mothers are the majority in rendering care in the homes. The Self-carers were mostly widows and single men who had no one to care for them in the home. "Others" included friends, brothers, grand-parents, etc, who were compelled to assume the responsibility of caring for the patients in the home, because there was no one else to do so.

**Table 7: SOURCE OF INCOME OF THE CAREGIVERS**

| SOURCE | FREQUENCY | PERCENTAGE (%) |
|---|---|---|
| Employment | 10 | 20 |
| None | 9 | 18 |
| Relative | 6 | 12 |
| Rent out room | 8 | 16 |
| Marketeer | 6 | 12 |
| Other | 3 | 6 |
| **TOTAL** | **50** | **100%** |

In this table only 10 (20%) Caregivers were in employment. Over 50 percent of the employed were the selfcarers, who would go to work when they were feeling better and get sick days off, when they were unwell. Some in this group said they were harassed at work and paid a half salary or only paid for the days they reported for work. The 9 (18%) who had no source of money, relied solely on the food that is distributed by Home Care Team.

Those who had two rooms or more, would rent out one room and use one room for the remainder of the family. Marketeers were unable to go to the formal market to sell their products because they could not leave the patient unattended. So they made markets in front of their homes, but their income was small. Some relatives would help the Caregiver, with money or food but in over 50 percent cases, the help was irregular due to the poverty of the Providers.

**Table 8:COMMON SYMPTOMS ENCOUNTERED AND THEIR REMEDIAL PRACTICES BY THE CAREGIVERS**

| SYMPTOMS | FREQUENCY | PERCENTAGE | REMEDY |
|---|---|---|---|
| Fever | 19 | 38 | Clinic |
| Diarrhoea | 18 | 36 | Clinic |
| Coughing | 16 | 32 | Clinic |
| Body pain and aches | 16 | 32 | Clinic |
| General body weakness | 13 | 26 | Hospital |
| Loss of weight | 10 | 20 | Soya meal |
| Mouth sore | 9 | 18 | Clinic-Salt gargle |
| Difficult in breathing | 6 | 12 | Clinic/ Hospital |
| Others | 8 | 16 | Clinic/ Hospital/ Homecare |

This question more than one response. "Others" included swelling of abdomen, paralysis of a part of the body, cramps, anaemia or leg pains.

About 40 percent of the respondents had been trained by Home Care on the use of home remedies for various symptoms. If they went to the clinic or hospital, with their sick relative, they were exempted from medical fees. Besides this, the Home Care team were visiting them regularly and would give them the required medicines as they were available. So despite their knowledge, they never used the home remedies. Some said it was too expensive to make, for example oral rehydration solutions require sugar, salt, soda and charcoal to boil the water. These items were unaffordable by most of them.

**Table 9:PROBLEMS FACED BY CAREGIVERS WHEN LOOKING AFTER PATIENTS IN THE HOME**

| PROBLEM | FREQUENCY | PERCENTAGE (%) |
|---|---|---|
| Lack of help from family | 35 | 70 |
| Unfriendly neighbour | 23 | 46 |
| Lack of food | 39 | 78 |
| Lack of medicine | 43 | 86 |
| No money for patient | 40 | 80 |
| Lack of knowledge | 20 | 40 |
| Lack of knowledge and skills | 17 | 34 |
| Other | 50 | 100 |

The above are frequencies of responses to the predetermined statements. The respondents were required to agree or disagree with the statement.

These results show that careproviders have significant problems as they look after the patient in the home. Nkowane (1990) found that 70 percent of care-providers had no support from relatives.

**Table 10: SERVICES OFFERED BY HOME CARE TEAM AND THE *NEEDED SERVICES BY HOME BASED CAREGIVERS***

| **Service by Team** | **Extra service needed** |
|---|---|
| Counselling | Home care office and Nurse/ Counsellor in the community |
| Food supplies | More food distributions |
| Education and training | Income generating training Small loan facility |
| Medicines | Transport for hospital reviews |
| Friendship and emotional support | Small token payment for non-relative Caregivers |
| Blood Tests for HIV | Gloves blankets and tolietries for use on the patient |

Despite the services that the Family Health Trust provide, Caregivers listed other needs as shown in the table above.

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# CHAPTER 6

## Discussion of results

## 6.1 **Problem of referral**

For a patient to benefit from the service of Home Care, they must be referred to Home Care. In this study, those interviewed were referred to Home Care by:-

- churches,
- relatives,
- self-referrals,
- neighbours,
- Home Care Team, and
- Others.

"Others" included other Caregivers, doctors, ward sisters, parents and individuals such as friends.

It is apparent from the above list that there are various referral sources to Home Care. The first problem with this type of referral system is that, it is not possible to plan home care for everyone. At the moment, Home Care has no clear cut policy or set guidelines on referrals, admissions and discharges. Patients referred through one of the stated channels, are registered and later on visited, assessed and admitted by the zonal Nurse/Counsellor. The problem of this kind of referral is that, on some days, the Home Care is overwhelmed by numerous referrals and consultations coming from different areas. The criteria used is that anyone who has tested HIV positive is accepted.

Delay and uncertainty about policy, have an effect on record keeping. There is usually a discrepancy between the records of the zonal Nurse/Counsellor and the Home Care Master Register. Sometimes, community care givers refer patients to Home Care through the Zonal Nurse and they are not entered in the Master Register. This distorts the monthly returns, but corrections are usually made since the problem is known. The data is used in the trust for their own planning and excution of services.

Medical referrals are another problem, as often Doctors never read the patients' previous notes to see whether that patient had been visited by Home Care Team, following their consultation request. As a result, they may end up referring the same patient three or four times to Home Care. By the time the Home Care realises this, the patient would have been recorded as "New Referral" for that particular month, three or four times. Patients referred to Home Care are often very ill. Some die on the wards before the Nurse/Counsellor gets to see them on the wards. Some die in the homes upon discharge before the Nurse/Counsellor pays them a visit. This poses a problem because, in the absence of the Referral Policy, people are not fully aware of the benefit of Home Care and do not seek the services early enough.

For example, in December 1996, there were 47 new referrals to Home Care and the total number of deaths recorded for the same month was 31. This shows that 66 percent died in that one month, both new and old clients. This is an example of the pattern of deaths that occur under Home Care.

In the Matero zone during data collection, one client who had not accepted Home Care, was asked to state her reasons for refusing. She said that "I cannot accept Home Care because Home Care means death. Can't you see that everyone who is under Home Care and is visited by those nurses with their bags of medicine never survives?" Since patients are referred in their terminal stages of their illness, they obviously die soon after being admitted under Home Care. If the referral system was adequate, patients could be referred as soon as they were diagnosed as HIV positive. This Matero Zone client assumed that Home Care Nurses are mandated by the Government to offer euthanasia to AIDS patients.

There can be problems of sharing real diagnosis at referral with caregivers. The patients are told about their status and diagnosis of AIDS, but the patients never tell their relatives or the would be Primary or Secondary Caregivers. Of the 50 primary Caregivers who were interviewed, 9 (18%) said their patients had AIDS. Over 50 percent said that their patients had TB.

Some were mentioning symptoms such as diarrhoea, or general body weakness, as their patients' diagnoses. This affects the impact of HIV/AIDS control and overall prevention programmes. Finally, one other problem of referral is that, patients lose contact after they have accepted the services of Home Care. Several reasons are given. The Home Care Services no longer provide discharged patients with transport to their houses. Patients are then asked to request a relative to return to home-care and provide directions to the patient's home. They fail often to do so.

## 6.2 **Problem of symptom management in the homes**

The common symptoms that Caregivers encountered, have been given in Table 8. The Caregivers expressed their resource needs in response to the question that asked them to state what they required to be able to care for the patient better, in addition to the home care team provision. The responses varied according to needs. 10 percent said they needed assistance with blankets and other bedding. These care givers said their patients had to make do with a piece of "chitenge" cloth to cover while they lay on the reed mat without anything on it. This was really a pathetic situation, especially for those who had patients who had diarrhoea. Lacking basic bedding was very stressful for caregivers. The problem was compounded by the distance from the water source in some cases.

In one zone, the Caregivers said they only had enough water for the patient and not the household members for use, because water only came every three days. This was a problem because most families were poor and had no big water storage buckets. In another zone, Caregivers said they had to pay monthly for water to the "Community water vendor". They were required to pay ZK2,000.00 per month. They said they could not afford this because they were poor. As a result, they resorted to walking long distances to draw water from a free source. This was exhausting and stressful for them. They said they were worried to leave their very ill patients unattended while they went to do other chores for the benefit of the whole family, especially the patient.

The other need expressed was lack of food even though they were getting food supplies monthly, they said it was not enough. Although the food given by Home Care was meant for the patient only, all family members had to eat this food. Some Caregivers said on some days, the patients had to go without food and medicine. They said that, some medicines required that they be taken after food, especially the TB drugs. So, medicines were omitted until food was available. In Chawama Zone, one very young caregiver said her family and the sick husband had to walk to the parents home to have meals because they had no food in the house.

Her husband had lost employment due to illness. Asked why they could not ask for raw food so that they could cook it for themselves, she said it was cheaper to share the cooked food.

Caregivers felt that they were at risk of contracting the HIV infection as they cared for their sick patients. They requested that Home Care should if possible, provide them with soap and gloves because they were part of HIV/AIDS control measures. Washing and bath soap, including gloves, were not priorities when money was available, but on the other hand most Caregivers admitted that they needed these things for hygiene and prevention of the spread of the disease.

The need for a Community Home Based Office was expressed by 3 (6%) of the Caregivers. They said when the Home Care Team was visiting other compounds away from them, they faced problems when their patients developed new symptoms. They, therefore, suggested that there should be a Home Care Office in each compound where everyone could go to seek help, in the absence of the UTH Home Care Team. About 18 percent of the Caregivers suggested that it would be helpful if the government could give them a loan scheme which could be administered by an agent such as Home Care. They said money to buy basic requirements, was hard to come by, but if they could start income generating ventures individually or collectively, this problem could be alleviated or even overcome.

Those in the higher educational level group, appeared to need counselling and education as opposed to material things such as food. Those with primary or no education, wanted material things such as food, transport and toiletries.

### 6.3 **Problems of families and relatives**

People with AIDS need a lot of care empathy and love. In addition, the Caregivers need assistance in caring for the patients. This assistance is both material and physical. In table 9, 70 percent of Caregivers interviewed, said they lacked help from family members in looking after the patients. One Caregiver in Kanyama Zone, had her house adjacent to her brother's grocery shop. She complained and said, "Look at that grocery, it is my brothers, but he cannot help me even with a loaf of bread. He expects me to buy everything from him, yet he knows I have no money." This same Caregiver complained how no one came to visit her and the patient. Nkowane (1990) also found that Family Support was lacking among Careproviders.

Another problem with the relatives is that they isolate the Caregivers. One mother who was nursing her daughter in Kabulonga Zone, said that no relatives came to visit her and they blamed her for her daughter's illness. They said she was not firm enough with her daughter. This upset her because, the opposite was the truth.

During the interview she said she nurses her daughter for the sake of the family comfort. She said she did not want to see her daughter lose so much weight and develop body rash which was often a problem with her daughter. She said, "I do not want my house to smell of death. You know, I get so upset with this child because, as soon as she feels better, she goes back to the street to get more illness."

Some caregivers felt so hopeless that they wished death could take away their relatives sooner. When asked for their reasons for such a wish, one Caregiver (an aunt) said that since AIDS had no cure, it would be better if "God took away" the sick person so that the money could be spent on other orphans' education.

During the interview, over 60 percent of the Caregivers, appeared to be under stress in one way or another. Some said they were physically depleted, some had psychological and social problems. One patient in Kabulonga Zone complained about how her mother would leave her very early in the morning to drink "kachasu" (local gin). She said, all the little money that came in, would be spend by her mother on alcohol. Alcohol abuse can be a manifestation of burnout, in some cases. Some Caregivers experienced problems from relatives and neighbours. About 23 (46%) of Caregivers, said their neighbours were unfriendly. In some cases, neighbours even verbally abused the affected family.

One Caregiver said each time she washed soiled beddings and hung them on the line, the neighbours would demand that she hangs them out of their sight because they were "repulsive" to look at.

The other problem of relatives and their patients was lack of recreation. Some Caregivers in the shanty compounds, had TVs, Videos, Radios, even some books. They could not use these items because they had no electricity. When asked why they bought these items when they knew that they had no electricity, they said that these items were not bought, but inherited from their deceased relatives. In some cases, dead spouses had left these items for the future use of their children.

### 6.4 **Problems of accommodation**

One of the questions on the interview schedule asked how many adults and children lived in the household. On the checklist, the Caregiver had to state the number of rooms they had and whether the patient had a separate room or not. Only 17 (34%) had a separate room for the patient. Self-carers constituted a larger number of these. Others had a separate room, not out of need, but they were given it by relatives who feared to contract the disease if they shared the same bedroom with the patient. So, they preferred to be crammed in one room rather than share a room with the patient. Patients with own room had no care at night.

**FACILITIES AVAILABLE IN THE HOMES OF THE 50 RESPONDENTS**

| FACILITY | CUM FREQUENCY | PERCENTAGE |
|---|---|---|
| Total no. of rooms | 154 | 100 |
| Total no. of children | 198 | 100 |
| Total no. of adults | 164 | 100 |
| Total caregivers | 49 | 100 |

**NB.** One checklist was missed.

"Rooms in this study included sitting room, kitchen and bedroom, minus bathroom and toilet which were indicated separately. This was done so as to accommodate the shanty compounds where one finds that the entire family would live in one "room". Space was, therefore, a problem for over 60 percent of families. This meant that the 198 children and the 164 adults had 154 "rooms" between them. There was overcrowding in these homes, which made family members vulnerable to contracting other diseases such as TB.

### 6.4.1 **Water**

Water was a problem as well. It was as shown in the table below.

| WATER SOURCE | FREQUENCY | PERCENTAGE |
|---|---|---|
| Communal tap | 21 | 42.9% |
| Water inside | 12 | 24.5% |
| Tap outside | 10 | 20.4% |
| Bore-hole | 3 | 6.1% |
| Well | 3 | 6.1% |
| **TOTAL** | **49** | **100%** |

**NB.** One checklist was missed.

The commonest water supply source was a communal tap as shown above. In some cases, the communal tap was situated quite a distance away from the house. Some Caregivers had to make several trips per day because they had inadequate water storage containers, and they needed so much water because of the patient and the large household size. Some Caregivers faced a problem of water shortage. In one zone, at the time of data collection, water was only turned on every three days. In another, the water vendor had turned off the communal tap because of non-payment by community users of ZK2,000.00 each. The wells had problems of irregular chlorination in one compound. The Caregivers were, however, aware of the cholera epidemic and they would boil the drinking water for their patients. This resulted in further stress and inadequacy in providing care in the homes.

6.4.2 **Toilets**

| TYPE OF TOILET | FREQUENCY | PERCENTAGE |
|---|---|---|
| Pit latrine | 23 | 46.9% |
| Waterborne | 21 | 42.9% |
| Others | 5 | 10.2% |
| **TOTALS** | **49** | **100%** |

**NB.** One checklist was missed.

Not every caregiver had a toilet. The availability of toilet is shown in the table above. "Others" included those who had no lavatory. They used the surrounding bushes or had to ask some friendly neighbours for use of their facilities. This was a problem for the patient who could not walk to the bush. The pit latrines were in most cases, shared (55%). There would be one pit latrine between three or four households. Some Caregivers said their patients were too ill to maintain balance while using the pit latrine. Some could not even squat, so they could improvise by using old newspapers which they could then dispose off in the pit latrine.

6.4.3 **Lighting**

| TYPE OF LIGHT | FREQUENCY | PERCENTAGE |
|---|---|---|
| Electricity | 23 | 46% |
| Candles | 16 | 32% |
| Paraffin lamp | 11 | 22% |
| **TOTAL** | **50** | **100%** |

Three main types of lighting used as shown above.

### 6.4.4 Cooking/Heating

| TYPE | FREQUENCY | PERCENTAGE |
|---|---|---|
| Charcoal burner | 30 | 60% |
| Electric stove | 9 | 18% |
| Electric hot plate | 9 | 18% |
| Firewood | 2 | 45 |
| **TOTALS** | **50** | **100%** |

Some patients need to warm their bodies from time to time despite the warm weather, and because some have inadequate warm beddings. There were four main sources of energy both for cooking and warming. Those who used charcoal complained at the expense of this commodity. They said the charcoal prices had gone up by 100 percent (100%) when fuel prices went up. Transporters demanded more money from the charcoal sellers who in turn, transferred the cost to the consumers. Those who used firewood said they had to walk long distances to fetch a bundle of firewood. In some cases they used anything like pieces of plank or other dry wood they could come across. There was a problem with those who used firewood and charcoal when they needed to cook anything urgently for the patient. It would take a long time for the charcoal burner or the wood fire to light. Once the cooking was over, there was no way of saving the remainder of the charcoal, but the firewood would be quenched with water and used at a later stage. Those who used electricity found a problem with payment of bills.

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## 6.5 Other problems

Some Caregivers said they had fear of contracting HIV/AIDS. Those who feared were two groups. One group were those who were ignorant, because they had not attended any Home Care Course, workshop, or seminar. The other group were those who had attended Home Care Workshops, seminars or trained in the home. These are knowledgeable on modes of transmission and prevention of risks. Their problem was lack of resources, such as toilet soap, gloves and disinfectants. They said they would rather buy food for the patient as opposed to gloves.

### 6.5.1 Transport problems

Transport was a major problem for the Caregivers. Sometimes the patient would need to go to the clinic, and the caregiver would have no money. In some cases, a wheel barrow with a cushion would be used. Some patients would be carried on the back of Caregivers. When a patient died in the home, and the body had to be moved, the taxi fare was **doubled.** It appears that this was a deliberate move to deter the Caregivers from using this transport. Taxi drivers, thought they would lose business because people would think that the taxi was infected, after carrying a body of a person who died from AIDS.

### 6.5.2 Stigma

Caregivers were asked what their patients were suffering from. As stated earlier, the majority mentioned TB. It would appear that most people, for fear of AIDS, which has no cure at the moment, find it comfortable and acceptable to mention TB. It would appear also that, despite the fact that TB is infectious, the Caregivers were at ease with nursing a TB patient rather than the patient with AIDS.

### 6.5.3 Caring for people with AIDS - Is it an industry?

Conducting research in the area of HIV/AIDS, seems to be an impossibility. Some organisations are reluctant, probably due to the notion of mistaking **research** for **auditing** of their activities. The question that one can ask is whether really there is advocacy and total commitment for the people with AIDS and their Caregivers in the homes.

# CHAPTER 7

## Summary and Recommendations

## 7.1 **Summary**

Although this study had its limitations, it has revealed that caring for people living with HIV/AIDS poses many challenges for care providers, be it in hospital or in the home. AIDS is a mortal disease with no effective cure in Zambia today. HIV/AIDS stresses the Caregivers in the light of poverty, ignorance and lack of material and emotional support from the Government and family. Caregivers, experience loss in terms of income, deaths of very young potential future leaders, contributors to the economy. In some cases, the youthfulness of the infected relatives, and stigmatisation, result in burnout of the Caregivers who have little or no coping mechanisms. The consequences of all these, affect the quality of care for the people with AIDS in the homes. Caregivers need "CARING" too.

## 7.2 **Recommendations**

### 7.2.1 **To the Government**

Since the Health Reforms have now been implemented and the Home Care strategy endorsed, Government can now formulate a policy and guidelines on the running and management of Home Based Care Programmes.

### 7.2.2 **To the Home based care programmes**

There should be flexibility of access to these programmes so that approved researchers can be of assistance in improving services by providing data based recommendations to ~~various Home Care programmes.~~

Globally, it has been agreed that, there should be "a human face" attached to HIV/AIDS pandemic, in terms of caredelivery. HIV/AIDS should be treated like any other disease to remove stigma.

### 7.2.3 To the Health Management Boards

Since the task of managing health issues has been decentralised, there is need to look into the local organisation of both Primary and Secondary Care-providers, including volunteers. There should be a multi-sectoral approach between different ministries. All health centres should develop a specialised referral policy regarding Home Care patients.

### 7.2.4 Plight of secondary caregivers

Secondary Caregivers who are church or other volunteers said they were disinclined to work with primary Caregivers because, there was no incentive from the Government. One secondary Caregiver who acted as guide in the Chawama Zone, said she had to put in so much, yet the Government has not recognised their efforts as community health workers. Her husband, who had just arrived from a visit, also complained of the same and added that, when his wife was away on this voluntary work, he had to cook for the family. In Matero Zone, the research team learned that there was a high dropout rate among voluntary Secondary Caregivers. The main reason for drop-out, was lack of incentives.

Globally, it has been agreed that, there should be "a human face" or removal of stigma attached to HIV/AIDS pandemic, in terms of care delivery. HIV/AIDS should therefore be treated like any other disease to remove stigma.

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## 7.3 **Generalisation of this study**

The findings of this study cannot be generalised for the whole of Lusaka. They, however, give a general overview of the problems of patients and their primary Caregivers in the homes. There is need in future to carry out another similar study to cover all compounds in all Zones, so that, more information can be available regarding needs of Caregivers. In future, a cohort study can be carried out on a group of people from all social-economic classes, so that needs and required coping mechanisms of individuals and various groups could be assessed. This study can also be conducted outside Lusaka. For example, in a rural area where the incidence of HIV/AIDS is high, or in a place where there is an established Home Care Programme. It would also be interesting to conduct a study on the patients themselves, to assess their needs, perceptions, worries and their feelings about the Home Care Programme.

## 7.4 **Interpretations**

One surprising outcome of this study was the fact that, there was little or no use of simple "home remedies" which are commonly used in most parts of Zambia. One would expect that this would have been cheaper, but it was the opposite. For example, it was cheaper to obtain ORS from the clinic or Home Care, rather than find ingredients to make home made ORS.

The magnitude of the urban poverty in Zambia became real during this study. The Zambia Poverty Assessment (1994), says that,

> "most urban poor, live in unplanned squatter settlements on the peripheral of urban centre, where lack of legal status service provision constrain their productivity. The insecurity is compounded by poor transportation services, lack of police protection and poor infrastructure, all of which force women to attempt to make a living out of their homes and keep girls out of school".

Statistics in this study showed that this was the real situation faced by home based caregivers.

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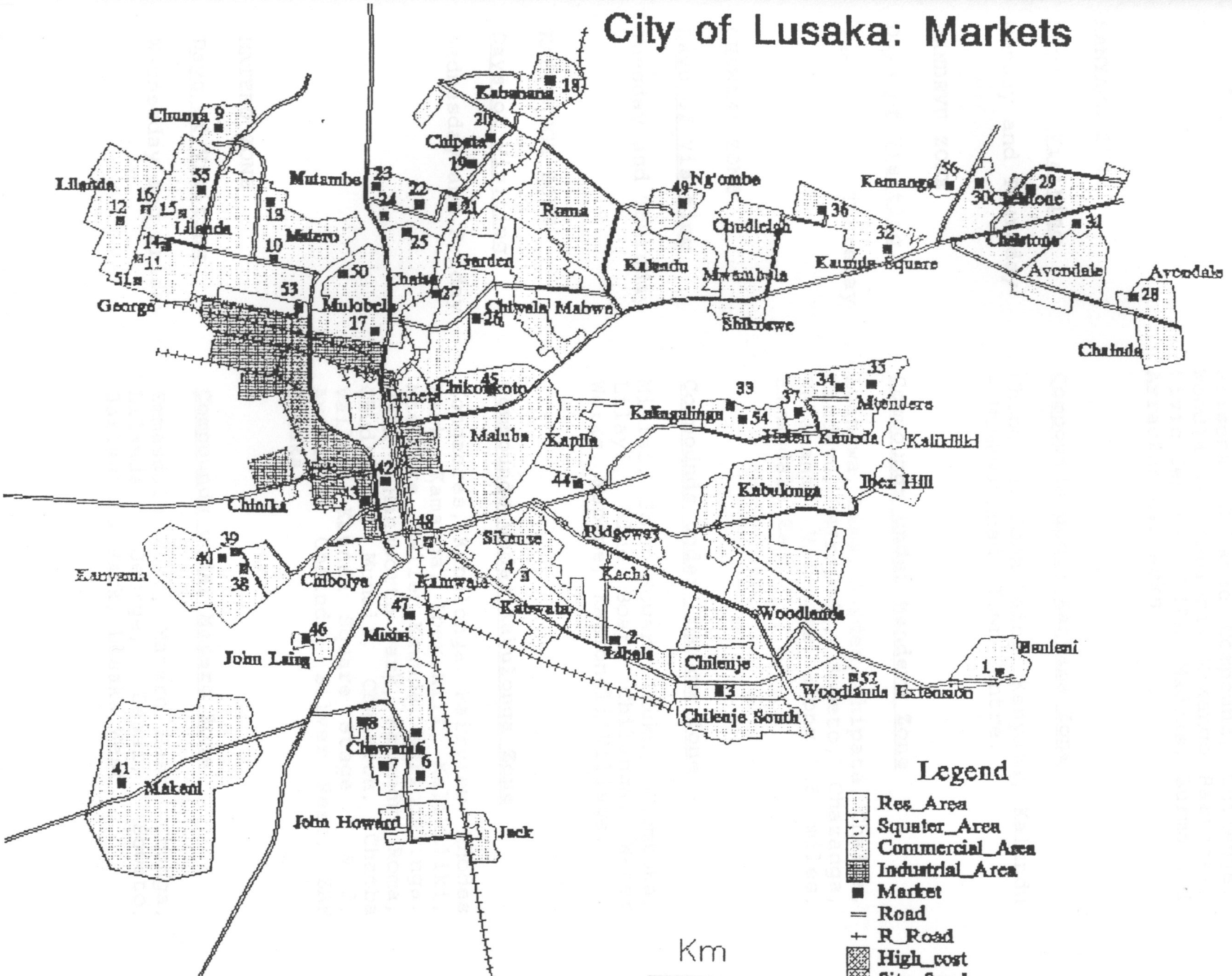
# City of Lusaka: Markets




## Legend

- Res_Area
- Squater_Area
- Commercial_Area
- Industrial_Area
- Market
- Road
- R_Road
- High_cost

1. Banleni
2. Libala
3. Chilenje
4. Kabwata
5. Lunumba
6. Chawama Main
7. Chawama Central
8. Kuomboka
9. Chunga
10. Matero
11. Kalukunga
12. Tambalala
13. Chingwere
14. Mwaziona
15. Desai
16. Lilanda
17. Chilondo
18. Kabanana
19. Chipata 1
20. Chipata 2
21. Marapodi
22. Mandevu
23. Ufulu
24. Gura
25. Chaisa
26. Chinyano
27. Mwasanka
28. Chainda
29. Chelstone
30. Chelstone 1
31. Avondale
32. Njati
33. Kalingalinga
34. Mtendere 1
35. Mtendere 2
36. Kaunda Square
38. Kanyama 1
39. Kanyama 2
40. Kanyama 3
41. Makeni
42. Town Centre
43. Chibolya
44. Longacres
45. Northmead
46. John Laing
47. Misisi
48. Lubuma
49. Ng'ombe
50. Bauxadale
51. Railway Side
52. Nyumba Yanga

**FAMILY HEALTH TRUST**
**ZONES VISITED**

**KABWATA ZONE**

| Days of Visiting | Compounds under Kabwata Zone |
|---|---|
| Monday and Wednesday | Kamwala, Kabwata, Hospital Compound/-Prisons, Sikanze Compound, Chilenje, Woodlands, Bauleni, Mikango Barracks, Civic Centre - NIPA, Madras, Burma and Arrackan Barracks. |

**KANYAMA ZONE**

| Days of Visiting | Compounds under Kanyama Zone |
|---|---|
| Monday and Thursday | Chibolya, John Laing, Kanyama, Kalundu - Mumbwa Road, Town Centre. |

**MANDEVU ZONE**

| Days of Visiting | Compounds under Mandevu Zone |
|---|---|
| Tuesday and Thursday | Luangwa, Lima, Garden, Chipata, Chaisa, Mandevu, Marapodi, Soweto, Chazanga, Kabanana, Villages along 15 miles, Emmasdale East. |

**CHAWAMA ZONE**

| Days of Visiting | Compounds under Chawama Zone |
|---|---|
| Tuesday and Thursday | Misisi, John Howard, Kuku, Kuomboka, Lilayi, Blue Boar, Chilanga, Water Works, Mapepe, Kazioneli Village. |

**KABULONGA ZONE**

| Days of Visiting | Compounds under Kabulonga Zone |
|---|---|
| Wednesday and Friday | Longacres, Kabulonga, Fairview, Rhodes Park, Kamanga, Ibex Hill, Kalikiliki, Mtendere, Hellen Kaunda, Kalingalinga, UNZA - Hansworth Park, Kalundu, Roma, Chudleigh, Munali, Chelston, Chamba Valley, Kaunda Square Stage 1 & 2, Avondale, Chainda, Silver Rest, ZAF Lusaka. |

**MATERO ZONE**

| Days of Visiting | Compounds under Matero Zone |
|---|---|
| Wednesday and Friday | Emmasdale West, Matero East, Chunga, Lilanda, George, Desai, Soweto, Barlastone Park, Lusaka West. |

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

December 9, 1996

To:.....

.....

.....

Dear .....

**PERMISSION TO CARRY OUT A STUDY ON SYMPTOM MANAGEMENT PRACTICES AMONG HOME BASED CARE-GIVERS**

I am a Post-graduate student in Masters of Public Health at University of Zambia. For my dissertation, I have chosen to look at the Home Care Services. I would like to assess the resources available to them in the home, and also to find out the material and emotional support they have from various people and organisations, including their families.

The research will entail interviewing the Primary Care-giver, that is the person who looks after the patient in the home day and night. There is also a checklist to assess the environment around the home, such as access to water or Health Centre, etc. The last method will be a focus group discussion with the Nurse/Counsellors, to find out the successes, failures, problems and constraints they may have in running the Home Care Programme.

Confidentiality will be maintained and informed consent will be obtained from all respondents. The Research, Ethics Committee has already approved the study. If permission is granted, I hope to conduct the study between December 1996 and February 1997. If permission is granted, I would request to be introduced to the Caregivers through your Home Care Focal person/persons.

Thanking you in advance.

Yours faithfully,

**Hilda V Kaunda (Ms)**

cc Dr N Ng'andu - MPH Co-ordinator
cc Dr K S Baboo - Supervisor
cc Prof P Sims - Lecturer - Community Based Education Unit

# THE UNIVERSITY OF ZAMBIA
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Department of Community Me
P.O. Box 50110
Lusaka, Zambia

Your Ref:

Our Ref:

17th December, 1996.

Ms. Ohline Lissane,
Home Care Programme Director,
Hope House,
Luanshya Road,
LUSAKA.

Dear Ms. Lissane,

STUDY ON SYMPTOM MANAGEMENT PRACTICES AMONG HOME BASED CAREGIVERS: BY MISS HILDA KAUNDA

I would like to introduce the above named Master of Public Health Student. She is also a Registered Nurse, Registered midwife, holds a Degree in Nurse Education and diploma in Counselling obtained from Kara Counselling, Thornpark Hall. For her dissertation, she has chosen Home Care as her area of interest and concern. At the moment, there are only two well organised Homecare programmes, that is your organisation and that of Family health Trust. Your organisation is even wide spread with twenty-eight (28) programmes under your co-ordination. In view of this, I write to request that Ms. Kaunda be introduced to individual programme managers in your organisation with a view to get permission from them. Please find a sample of the standard letter which would be sent to individual managers to ask for permission.

Please find enclosed a summary of the research proposal approved by University of Zambia Research Ethics Committee. Confidentiality will be maintained throughout the study. Anonymity of the respondents will also be ensured throughout the study. NASTLP is funding this study.
Time allocated by the University for this study is from December 1996 to February, 1997.

Yours faithfully,

Dr. Nicholas Ng'andu
MPH - COORDINATOR

c.c. Ms. H.V. Kaunda - MPH student - UNZA

Office 260 1 239257/239353
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P.O. Box 32
10101 Lusak
Zambia

# *ARCHDIOCESE OF LUSAKA*

**Community Home Based Care Programme**
**Coordination Office**
**Baptist Building**
**Plot No. 3016/2**
**Makishi Road**
**Lusaka**
23-1-97
**Tel: 222492**

Dr. Nicholas Ng'andu
Department of Community Medicine
P O Box 50110
Lusaka

Dear Dr. Ng'andu

**RE: STUDY BY MISS HILDA KAUNDA**

I refer to your letter of 17th December, 1996, with regard to a study of symptom management practices among Home Based Care-givers.

Miss Kaunda has requested permission for access to our patients homes to interview the primary care-givers of AIDS patients which is in most cases a relative of the chronically ill patient. In order to protect the confidentiality of our patients in the community, and the trust they have in us, our management group has refused this request.

However, we do feel that if the design of this study were to include interviewing the practices of secondary care-givers, then a selection of our 100 community volunteer care-givers could be interviewed.

Our volunteers provide support in the home of the patient to both the patient and the primary care-giver (relative) with a wide selection of practical help, nursing care, psychological support, welfare support and AIDS education counselling.

As Miss Kaunda has reportedly interviewed the Home Based Care team from the hospital, it is my opinion that a gap would exist in this study should Community Home Based Care groups be not reflected, causing the study to be invalid.

I would also like to address a small but significant inaccuracy in your letter, which points to Family Health Trust and the Archdiocese Community Home Based Care Programme as the only two organised home care programmes. This may be true for Lusaka urban at present, but is wholly inaccurate for Zambia as a whole.
The Salvation Army run a rural Home Based Care Programme out of Chikankata, and the Catholic Diocese of Ndola has one of the largest home care programmes in all of Africa, and is a model from which other programmes in Zambia and Africa-wide are learning from.

I offer these points for your consideration. I am sorry if any inconvenience is caused by our not being able to comply with your request to interview patient care-givers.

Yours sincerely

for Justina Chanda

Lisanne O'Loughlin
**HBC PROGRAMME MANAGER**

File: letter9.doc

**UNIVERSITY OF ZAMBIA**
**SCHOOL OF MEDICINE**
**DEPT. OF COMMUNITY MEDICINE**
**P O Box 50110**
**LUSAKA**

**Dear Respondent,**

I am a student of Masters of Public Health from the Department of Community Medicine, in the School of Medicine of University of Zambia.

I am undertaking a research among Homebased Caregivers of chronically ill patients in the homes. The research is looking at how home based caregivers manage the symptoms or problems that are connected with the chronic illness. This will include assessment of the resources that are available to CAREGIVERS, and also the support that they receive from the various people in the community, including family members.

The information required will be collected using a questionnaire, which has three parts. The first part asks for your personal details, **but not your name.** The second part asks about the patient you are looking after, and the last part examines the support you get. I have also attached a checklist for you to tick the facilities that are available to you here at home.

The interview will take about 30 minutes. You are free to answer all or some questions of your choise. You can stop the interview at any point if you choose to do so. The information you give me, will be treated with **maximum confidentiality**, and will be used to improve the home care services, when and if accepted by the programme managers. The information you give me should, therefore, be freely given.

You are free to choose to participate or not to participate. If you choose to participate, or refuse to participate, you will not suffer any penalty or loss of benefits to which you are entitled from the Home Care Services.

If you are willing to participate, please sign below, after reading the statement.

## CONSENT TO PARTICIPATE

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

Signature or Thumb print.....
Date.....

Serial NO of client.....

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

Miss Hilda V. Kaunda
School of Medicine
Department of Community Medicine
P O Box 50100
LUSAKA.

**THE UNIVERSITY OF ZAMBIA**

SCHOOL OF MEDICINE
DEPARTMENT OF COMMUNITY MEDICINE
LUSAKA.

QUESTIONNAIRE ON THE STUDY OF SYMPTOM MANAGEMENT AMONG CAREGIVERS OF CHRONICALLY ILL PATIENTS IN LUSAKA URBAN SELECTED COMMUNITIES.

SECTION A: SOCIO-DEMOGRAPHIC DATA OF THE CAREGIVER.

Serial No. of Care giver: ###### Date: <dd/mm/yy>

a. Zone: _____ b. Religion: _____

2. a. Age: ## Sex: <A> Marital status: <A>

3. a. Tribe: _____ Relation to Patient : _____

4. What education level did you attain ?: _____

5. Are you in Employment ?: <Y>

6. If NO what is your source of income ?: _____

7. How many people live in this household ?: ##
   a. Number of Children ?: ##
   b. Number of Adults ? : ##

8. Have you ever attended a home based care course ?: <Y>
   Please give reasons for your answer..: _____

SECTION B: INFORMATION ABOUT THE PATIENT

9. What is the patient suffering from ?: _____

10. How long has the patient been unwell ?: _____

11. Who referred the patient to home care ?: _____

12. What sort of help did you expect from the Home Care Services ?: _____

13. Please tick yes or no if the patient has developed any of the symptoms listed below,

| | | | |
|---|---|---|---|
| 13.1 | Diarrhoea | : | <Y> |
| 13.2 | Fever | : | <Y> |
| 13.3 | Coughing | : | <Y> |
| 13.4 | Difficult in breathing | : | <Y> |
| 13.5 | Mouth sores | : | <Y> |
| 13.6 | Loss of Weight | : | <Y> |
| 13.7 | Genital Sores | : | <Y> |
| 13.8 | General body weakness | : | <Y> |
| 13.9 | Body pain | : | <Y> |
| 13.10 | Any Other | : | <Y> |

14. If you have tick Yes to any of the questions in question 13 above,please write below what home remedies you have been using for each symptom separately.

14.1 Symptom: _____

14.1.1 Home Remedy: _____

14.2 Symptom: _____

14.2.1 Home Remedy: _____

14.3 Symptom: _____

14.3.1 Home Remedy: _____

SECTION C CAREGIVERS SUPPORT SYSTEM

15. What problems do you face while looking after the patient at home?

Please tick Yes or No...

15.1 Lack of help in caring of the patient from my family and relatives: <Y>

15.2 Neighbours are unfriendly to us: <Y>

15.3 Lack of food in the home: <Y>

15.4 Lack of medicines for the patient: <Y>

15.5 Lack of money to buy requirements for use on the patient: <Y>

15.6 Lack of knowledge and skills to care for the patient: <Y>

15.7 Others (Specify): _____

16. How often does the home based care visit you in a week?: _____

17. What kind of help does the home base care team offer to you: _____

18. What other help would you like from the home base care team to offer besides what they offer to you?:

_____

19. Do any members of your community help you in any way? : <Y>
Give reasons to your answer:

_____

CHECKLIST FOR RESOURCES IN THE HOME

A INFRASTRUCTURE

1. Total number of rooms: ##
2. Separate room for patient: <Y>
3. Separate Bathroom/Showerroom: <Y>

B TYPE OF TOILET: _____

C WATER SUPPLY: _____

D LIGHTING: _____

E HEATING/COOKING: _____

F RECREATION: _____

# GUIDELINE FOR FOCUS GROUP DISCUSSION

1. **General comments on the Home Care Service**

   - Successes
   - Shortcomings
   - Constraints

2. **Referral system**

   - Knowledge of diagnosis by patient and family at referral
   - Who refers patients?
   - Self
   - Church
   - Doctors
   - Counsellors/Nurses
   - Family

3. **Lengthy time between referral and first-visit**

   - Reasons for stated period

4. **Empowerment of the Caregiver**

   - Discussion of discharge/future plans?
   - Knowledge?
   - Skills?
   - Initial resources given?
   - Training before discharge or after discharge?

5. **Support Caregiver/Patient**

   - Frequency of visits in a week?
   - Type of assistance at each visit?
   - Confidentiality
   - Record System/Statistics
   - Treatment Plan

6. **Home Staff Support**

   - Source of funding/resources
   - Motivation
   - Daily Problems/Solutions
   - Staffing Levels
   - Vision for Home Care

**BUDGET**

| | ITEM | UNIT COST IN KWACHA | QUANTITY | TOTAL COST |
|---|---|---|---|---|
| 1 | STATIONERY | | | |
| | Typing paper | K10,500 / Ream | 4 Reams | K42,000.00 |
| | Duplicating paper | K10,500 / Ream | 3 Reams | K31,500.00 |
| | Duplicating ink | K9,000 / Tube | 1 Tube | K9,000.00 |
| | Stencils | K10,000 / Packet | 1 Packet | K10,000.00 |
| | Pens | K200 / Pen | 20 Pens | K4000.00 |
| | Pencils | K150 / Pencil | 10 | K1,500.00 |
| | Rubbers | K250 / Rubber | 6 | K1,500.00 |
| | Type Setting and binding services | K5 000 / copy K20 000/ | 15 copies protocols, 5 copies main study | K75,000.00<br>K100,000/ |
| 2 | SECRETARIAL SERVICES | | | |
| | Typing Services | K1000 / Page | 100 Copies | K100,000.00 |
| | Typing questionnaire Stencil | K1000 / Page | 100 Pages | K100.000.00 |
| | Focus Group Guidelines Stencils | K1000 / Page | 2 Pages | K10,000.00 |
| | Duplicating Service | K500 / Page | 320 Pages | K160,000.00 |
| | Data Entry | K50,000 | 2 Services | K100,000.00 |
| | Final Analysis Report | K100,000 | 1 Services | K100,000.00 |

| | | | | |
|---|---|---|---|---|
| 3 | PERSONNEL | | | |
| | Researcher - Meal Allowance | K10 000 / Day | 10 Days | K100,000.00 |
| | 2 Research Assistants - Meal Allowance | K10 000 / Day x 2 | 10 Days | K200,000.00 |
| 4 | TRANSPORT | | | |
| | Daily Data Collection in Compounds | K10 000 return daily each | 10 Days | K300,000.00 |
| | | | Subtotal | K1,525,500.00 |
| | | | 10% Contingency | K152,550.00 |
| | | | Grand Total | K1,678,050.00 |

**JUSTIFICATION OF THE BUDGET**

This budget is justified because it was drawn after doing a survey on current prices of services and commodities such as stationery. The study will be done in six zones, namely, high density, medium density and low density residential areas. In the high density areas, the houses are so far apart from each other, that one would need to use more than one mini bus to get to the different sections of the zones. In the low density, there are no mini buses that go into the residential areas, so there would be need to hire taxis. Computer and Secretarial Services have also gone up as indicated in the budget.

WORK PLAN

TABLE - II

| TASK | PERSON | AUG | SEP | OCT | NOV | DEC | JAN | FEB |
|---|---|---|---|---|---|---|---|---|
| 1. Finishing writing proposal | Researcher | | | | | | | |
| 2. Send letters of permission to relevant authorities | Researcher | | | | | | | |
| 3. Recruit and train assistants | Researcher | | | | | | | |
| 4. Pre-test | Researcher/ Assistant | | | | | | | |
| 5. Data collection | Researcher/ Assistant | | | | | | | |
| 6. Data analysis | Computer Analyst | | | | | | | |
| 7. Report writing | Researcher | | | | | | | |
| 8. Submission of report | Researcher | | | | | | | |
| 9. Feedback Submission | Researcher | | | | | | | |