HOME-BASED CARE PROVIDED TO HIV AND AIDS INFECTED PATIENTS IN ONANDJOKWE HEALTH DISTRICT, NAMIBIA

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Home-based care provided to HIV and AIDS infected patients in Onandjokwe Health District, Namibia.

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I hereby declare that this study of the home-based care provided to HIV/AIDS-infected patients in Onandjokwe Health District in Namibia is my own work and that the sources that I used or quoted have been indicated and acknowledged by means of complete references.

SUushona

Selma Ingandipewa Uushona

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DEDICATION

The book is dedicated to

- vulnerable children and orphans
- home-based care providers in the Onandjokwe Health District of the Oshikoto Region and elsewhere in Namibia, who are always willing to work as partners in health care provision

ABSTRACT

Namibia is a country with a high prevalence of HIV infection. Similar to many hospitals and health facilities around the country, Onandjokwe Health District is experiencing social, economic and health care problems related to HIV/AIDS patients. The home-based care option is seen as an alternative to cater for the needs of the HIV/AIDS patient with the support of family members and communities. People who are involved in providing home-based care are usually non-professionals caregivers who sometimes have little or no training with regard to the health care of HIV/AIDS-infected persons. The purpose of this study was to explore the home-based care provided to HIV/AIDS-infected patients and the problems caregivers face. The study was undertaken in order to meet the following specific objectives: to describe the profile of home-based caregivers of HIV/AIDS-infected patients in Onandjokwe Health District; to determine the knowledge home-based caregivers of HIV/AIDS patients in Onandjokwe Health District have about HIV and AIDS; to explain protective measures used by home-based caregivers of HIV and AIDS patients in Onandjokwe Health District; to explore the personal experiences of home-based caregivers of HIV/AIDS-infected patients in Onandjokwe Health District; and to identify the type of support provided to HIV/AIDS-infected patients by home-based caregivers .

A survey was conducted among selected non-professional caregivers in various villages of Onandjokwe Health District. A questionnaire that was developed in English and translated into Oshindonga to overcome a possible language barrier was used to gather the data.

The findings revealed that the majority of caregivers were females between 15 and 66 years. Primary caregivers were family members and relatives. The majority of the respondents was unemployed and poor, and survived in difficult conditions. The study revealed a lack of transport and that non-professional caregivers travelled long distances to reach health facilities. Many of them had inadequate training in home-based care and limited knowledge of HIV and AIDS infection.

The research findings reveal that home-based caregivers face problems in caring for patients at home in Onandjokwe Health District.

Some of the problems mentioned by non-professional caregivers included lack of resources such as money, food, medicine, home-based care kits and gloves; lack of information; discrimination; neglect; rejection and stigmatization. These problems prevented people with HIV/AIDS from looking for health care and social services in their communities.

One of the recommendations to improve home-based care is to develop strategies that will make it effective and sustainable at the community level. It is highly recommended that a partnership be established which will help to build collaboration between government, community groups and NGOs.

Keywords:
Home-based care, HIV & AIDS infected patients, caregivers.

LIST OF ABBREVIATIONS

AIDS - Acquired Immune Deficiency Syndrome

ART - Antiretroviral therapy

ARV - Antiretroviral

CAA - Catholic Aids Action

CBO - Community Based Organizations

CBHC - Community-based health care

EECMY - Ethiopia Evangelical Church Makane Yesus

ELCIN - Evangelical Lutheran Churches in Namibia AIDS Action

FHI - Family Health International

GRN - Government of the Republic of Namibia

HBC - Home-based care

HIV - Human Immunodeficiency Syndrome

ICASO - International Council of AIDS Service Organisations

MOHSS - Ministry of Health and Social Services

NANASO - Namibia Network of AIDS Service Organisations

NEPRU - Namibia Economic Policy Research Unit

NGO - Nongovernmental Organisation

PHC - Primary Health Care

PLWHA - People Living with HIV/AIDS

PPTCT - Prevention of Parent to Child Transmission

STD - Sexual Transmitted Diseases

STI’s - Sexual Transmitted Infections

TB	-	Tuberculosis
TKMOAMS	-	Tate Kalunga Mweneka Omukithi Gwo AIDS Moshigwana Shetu
UNAIDS	-	Joint United Nations Programme on HIV/AIDS
UNICEF	-	United Nations Children’s Fund
USAID	-	US Agency for International Development
VCT	-	Voluntary Counselling and Testing
WHO	-	World Health Organisation

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CHAPTER 1

BACKGROUND TO THE STUDY

1.1 **Introduction**

Many factors contribute to patients needing health care over an extended period of time. Some of these factors are terminal illness caused by cancer, cardiac conditions, tuberculosis (TB) and chronic infections resulting from AIDS (Young, Van Niekerk and Mogotlane 2003:198). AIDS is a complex disease that involves medical care, public health, the economy, social order and, inevitably, the whole area of morality (Directory 2004). As more people become infected by AIDS, current health institutions will no longer be able to cater for their admission needs (Young et al 2003:198). The problem of an increasing number of HIV/AIDS patients leads to the only other option home-based care. Home-based care uses home-based caregivers as a frontline and backbone to complement quality care. In order to meet the needs of HIV/AIDS infected patients and their families, a sincere call for community involvement and active participation is needed at grassroots level. Community and/or home-based care are viewed as alternative care settings that can offer sustainable and cost-effective care across the continuum (Young et al 2003:198).

If patients' conditions are not very critical, families should rather care for them at home. This reduces the problem of overcrowded hospital wards, overloaded workers in health facilities, high hospital costs and constant movement associated with visitors visiting the sick in hospital. Frequent hospital visits and the cost of medicine and treatment have huge financial implications on the infected that affect patients and family alike (Jariyavilas, Ngamkasem, Matnangkoon, Siripong, Pancharoen & Thisyakorn 2003:114).

In order to minimise the socio-economic implications of hospitalisation, home-based care is seen as the best alternative to it. Home-based care and community-based care are interrelated. One occurs within the context of the other (Young et al 2003:199)

Community-based care means providing the right level of intervention and support within the community setting to enable people to achieve maximum independence and control over their own lives. It also means being at home with the family who cares for the patient, help from outside, and care given by health professionals and/or volunteers with inputs from friends and families. Home-based care, on the other hand, refers to the care of the patient at the patient's place of residence and the use of community resources to render effective care.

Home-based care does not exist without problems. One of the problems home-based caregivers face is lack of resources. The resources include human resources, financial resources, material and equipment.

Despite limited resources, however, home-based caregivers are committed and dedicated in caring for HIV and AIDS patients. The home-based caregivers are doing their level best to fight the devastating disease and its detrimental effects on humanity.

As in many parts of Africa, the Onandjokwe Health District faces the problem of an increase in the number of HIV patients. This leads to overcrowded health facilities and it seems that professional caregivers are unable to cope with the increased number of HIV/AIDS-infected patients.

The Onandjokwe Health District is a rural health district in the Oshikoto Region, a northern part of Namibia (see annexure A). It is served by the Evangelical Lutheran Church in Namibia Mission Hospital, which is supported/subsidised by the government.

During 2004 the population was estimated at 147,179 people, as projected from the 2001 Census (District population group based on 2000 census, Onandjokwe Primary Health Care Quarterly Report 2004). The Namibian population stands at 1,826,854 people (GRN 2003b:2). The country has a relatively youthful population, with 43% of the population being less than 15 years of age and less than 4% being over 65 years.

According to Shapumba, Apollus, Wilkinson, Shifiona and Karirao (2004:1), young people make up the largest group of the Namibian population. They indicate further that approximately 72% of the population is in the adolescent and youth age.

It is vital to remember that they are not just the largest population in Namibia, but they also constitute the future generation of the country. However, their growth to adulthood is made uncertain by HIV/AIDS, STIs, STDs and teenage pregnancies (Shapumba et al 2004:3).

Namibia is severely affected by the HIV/AIDS pandemic, especially young men and women (Shapumba et al 2004:4). The country is ranked among the top five countries most affected by AIDS in the world and has a prevalence rate of 22.3%.

According to GRN (2004a:5), there are 10,228 orphans in the Oshikoto Region (where the Onandjokwe Health District is located). Most of these children are under 15 years. Whereas 9,288 children have lost one parent, 940 children have lost both parents.

The HIV/AIDS pandemic is the major factor that contributes to increased hospitalisation in Namibia: from 355 in 1993 to 6,878 in 1999, with patients needing care for a long time (GRN 2001b:1). Home-based care would therefore be the most cost-effective alternative to hospital care because it makes use of home-based caregivers caring for HIV and AIDS patients in the home environment. According to Otaala (2000:4), hospitalisation is an important indicator for the workload in hospitals and the overall burden on health services due to HIV/AIDS. He further indicates that in 1999 a total number of 6,878 persons were hospitalised for HIV and AIDS.

This is a continued increase from that of 1998 (a figure of 5,155 hospitalisations). The figure is also confirmed in the study done by Kasanda (2003).

The negative impact of the HIV/AIDS pandemic on all sectors of the Namibian economy is already felt and is expected to increase considerably over the next decade. All the levels and sections of the Namibian population are negatively affected by the spread of HIV and AIDS. Adverse effects on social cohesion, human development and economic advancement are some of the results of the pandemic. Notwithstanding strenuous efforts to curb the disease, the HIV/AIDS pandemic continues to spread and to snatch away loved ones, friends and neighbours. It was only in 1986 that people first learned and heard about the first four reported cases of HIV/AIDS in Namibia, but by 31 December 2003 a cumulative number of 136,068 HIV/AIDS-infected cases was recorded (GRN 2004a). Furthermore, the source indicates that HIV/AIDS infection is estimated at approximately 250,000 infected people.

Today women account for about half of the 40 million people living with HIV and AIDS (PLWHA) worldwide. In Sub-Saharan Africa, where HIV and AIDS transmission is predominantly heterosexual, almost 60% of the people living with the virus are women. Women are more susceptible to HIV infection because of biological, cultural and social factors. These factors include illiteracy and lack of skills to work outside the home, which force them to depend on men for economic support.

Inaccessibility to accurate and reliable information on HIV/AIDS prevention and lack of capacity to use protective measures against HIV infection also increase their vulnerability (ICASO 2004:21). According to Iipinge, Hofnie and Friedman (2004:1), women are physiologically, socially and economically more vulnerable to the impact of HIV and AIDS than men.

1.2 **Outline of the problem**

In the past community members believed that caring for patients and family members who were sick was a role that only health staff had to fulfil. Today demanding problems (eg the increased number of HIV and AIDS patients) have changed this belief. In the Onandjokwe Health District, Katonyala Home-Based Care and Primary Health Care are organisations that have a programme for home visits. However, they encounter obstacles such as a shortage of staff and lack of transport. Trained home-based caregivers and HIV/AIDS patients need visits from health personnel, but the health team depends on the availability of resources such as transport in order to do regular home visits.

Families are involved in caring for sick family members. Home-based care is chosen as an alternative to cater for patients’ needs. Home-based caregivers who care for HIV and AIDS patients do home-based care through voluntarism. This is confirmed and supported by a study done in a rural setting in South Africa.

According to Maimane (2004:526), thousands of unemployed South Africans work as volunteer community health workers for no pay and without training. These volunteers play a key role in HIV and AIDS care (particularly in remote rural areas), closing the wide gap between health systems and grassroots communities. The study also reveals that community health workers are called to attend to TB patients, and it is suspected that many such patients also suffer from HIV and AIDS. Much of their work involves very basic hygiene, such as going to the river to get water to bath a sick person and cleaning the house.

Some of the home-based caregivers were trained to do home care by non-governmental organisations such as Katonyala, TKMOAMS, Catholic Aids Action and ELCIN AIDS Action. Unfortunately not all home-based caregivers are trained. For the purposes of this study, the researcher investigated only the care given by trained home-based caregivers.

1.3 Statement of the problem

Home-based care includes community involvement in the health care services provided to HIV/AIDS-infected patients. People who are involved in providing home-based care are usually home-based caregivers. Most of these trained home-based caregivers still lack sufficient knowledge and skills regarding the health care of HIV/AIDS-infected patients.

Home-based care specifically needs people who were trained in a large variety of skills. Home-based care refers to a range of services provided to persons in their own homes which enable them to continue living as actively and independently as possible. According to Smith (2003:29), home-based care is comprehensive care given for the purpose of promoting, maintaining and restoring health; or maximising the level of independence while minimising illness. This shows that home-based care can include physical, social and spiritual (or mental) care. Social care includes giving emotional support. Physical care involves bathing, preparing meals and feeding, and keeping the home environment clean.

Because of the call for home-based care, there is now a tendency of discharging patients early who still need nursing care in health care facilities. In some instances, the family is unable to provide home-based care without financial assistance (Iipinge 2001:12). Quality home-based care can also be impaired by the lack of a communication system and a poor referral system at community level. Currently, home-based caregivers assist HIV and AIDS patients with difficulty. The difficulty arises from factors such as lack of information, knowledge and skills; lack of adequate resources; and the devastating nature of the illness (Jackson 2002).

1.4 Purpose of the study

The purpose of the study is to describe the home-based care provided to HIV/AIDS-infected patients in the Onandjokwe Health District.

1.5 Specific objectives of the study

The specific objectives of this study are to:

- describe the profile of home-based caregivers of HIV and AIDS patients in the Onandjokwe Health District (see section A[questions 1-9], section B [questions 10-18 and 25] and section C [questions 52-54] of the research questionnaire).
- determine the knowledge of home-based caregivers of HIV and AIDS patients in the Onandjokwe Health District about HIV and AIDS (see section B [questions 19-24] of the research questionnaire).
- explain the protective measures used by home-based caregivers of HIV and AIDS patients in the Onandjokwe Health District (see section B [questions 30-40] of the research questionnaire).
- explore the personal experiences of home-based caregivers of HIV and AIDS patients in the Onandjokwe Health District (see section B [questions 26-29, 35,41-48] of the research questionnaire).
- identify the types of support provided to HIV and AIDS patients by home-based caregivers (see section B [questions 49-51], section C [questions 55-56] and section D [question 57].

Flowing from the stated objectives, the following questions were investigated:

- What are the problems facing home-based caregivers in caring for HIV/AIDS-infected patients at home in the Onandjokwe Health District in Namibia?
- Do the home-based caregivers have knowledge about HIV and AIDS?
- What types of protective measures are available for use by the home-based caregivers?
- What are the resources available to home-based caregivers and how appropriate are they?
- What coping strategies do home-based caregivers use when dealing with their own physical, moral, emotional and social needs?
- What are the recommended strategies required to address the physical, moral, emotional and social needs of home-based caregivers?

1.6 **Significance of the study**

The study is crucial and important. It will assist in describing the problems home-based caregivers who care for HIV and AIDS patients at home face (such as knowledge of home-based caregivers about HIV and AIDS, protective measures used, personal experience of home-based caregivers and coping strategies used by home-based caregivers). Furthermore, it will describe the availability and the appropriateness of the support and resources home-based caregivers require. It will also recommend strategies to address the physical, moral, emotional and social needs of home-based caregivers who care for HIV and AIDS patients at home.

Based on the findings, strategies can be developed and used as a tool to guide and assist home-based caregivers in caring for HIV and AIDS patients within the home environment. Furthermore, the findings will be useful to policy makers in developing strategies to assist them in alleviating problems faced by home-based caregivers in caring for HIV/AIDS-infected patients and their families.

1.7 **Ethical considerations**

During the research study and throughout the research process, ethical aspects were maintained. Permission to conduct this study was sought from the Ministry of Health and Social Services, the Governor of Oshikoto Region and the Onandjokwe Primary Health Care (PHC) Supervisor. Participants were informed about their rights. Anonymity and confidentiality were ensured and maintained throughout the study (Bless & Higson-Smith 2000:101; Polit & Hungler, 1999:138).

1.8 **Definitions of key concepts**

Home care: Refers to the components of the continuum of comprehensive health care whereby health services are provided to individuals and families in their places of residence for the purpose of promoting, maintaining or restoring health; or for maximising the level of independence while minimising the effect of disability and illness, including terminal illness (Iipinge 2001:16; Smith 2003:28).

Home-based care: The care given to individuals in their own natural environment (their home), supported by families, skilled welfare officers and communities in order to meet their spiritual and psychosocial needs -- with the individual playing a crucial role (Lindsey, Hirschfeld, Tlou & Ncube 2002:489; GRN 2001b:9).

Home-based caregivers: Refers to the volunteers, friends and family members who provide for the physical, social, economic, psychological and spiritual basic needs of patients infected with the HIV/AIDS disease. In this study “home-based caregivers” means people trained by NGOs or home-based care organisations.

Human Immunodeficiency Virus (HIV): The virus that causes “acquired immune deficiency syndrome” (Nzimande 2003:36).

Acquired Immune Deficiency Syndrome (AIDS): This is an illness that impairs the body’s ability (defence system) to fight infection, with the result that the body is extremely susceptible to life threatening diseases (Nzimande 2003:36).

1.9 Summary

Namibia is a country with a high prevalence of HIV/AIDS. The result is that health caregivers cannot cope with the large number of seriously ill patients admitted to hospitals. In order to deal with this problem, a home-based caring approach is adopted. Because of the comprehensiveness of this approach, a well-organised structure is necessary to enable the effectiveness of care. It is not clear how well this approach is structured because it seems that home-based health caregivers experience major problems in caring for sick family members, even though some of them were trained. The purpose and objectives of the study were indicated.

CHAPTER 2

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1 **Introduction**

This literature review examines what is known about the problems home-based caregivers face. It also examines the role of home-based caregivers in the community and the hindrances that hamper the effective integration of home-based caregivers into the official government sponsored health care system. It also looks at possible strategies of facilitating well co-ordinated home-based care at community level and the coping strategies other countries use to sustain home-based care within their communities.

The researcher used the integrated home-based care model. This model works by linking all the service providers with the patients and their families in a continuum of care (Uys & Cameron 2003:5).

The model is applicable to this research study because it indicates how to promote mutual support and collaboration between various components (that is families, volunteers, health facilities, support groups, non-governmental organisations and government agencies). The integrated model facilitates a smooth referral system between all partners involved in home-based care.

It develops capacity among all partners involved in home-based care services and builds a foundation of capacity for home-based caregivers. The model ensures that home-based caregivers are trained and equipped with the essential knowledge and skills needed in the basic care of HIV/AIDS-infected patients. This assists in providing a backup system that will be maintained.

Health care professionals will take up the responsibility of supervising and supporting home-based care where needed. The use of the integrated home-based care model assists home-based caregivers to function as part of the health care team and to feel responsible for making the home-based care programme successful. It also helps the researcher to identify existing shortcomings in the home-based care programme in the Onandjokwe Health District. In other words, the care of home-based caregivers is essential and should be incorporated in the home-based care programme in order to prevent burnout, despondency and loss of capacity to provide compassionate care (Uys & Cameron 2003).

The integrated home-based care model illustrates clearly that the focal persons at the centre of the model are the patient who lives with HIV and AIDS, and his or her family. This small network is supported by a large and growing network of services, which should also be supported by the larger community. All the care is given based on palliative care standards, and is aimed at preventing the illness by increasing openness and understanding and thereby changing behaviour (Uys & Cameron 2003:6).

2.2 Overview of home-based care

According to statistics in the Summary Report on HIV Counselling for the year 2004 (Onandjokwe Health Information System 2000), the HIV positive result for males was 718 (32.5%), while the result for females was 1492 (67.5%). There is an increased number of HIV/AIDS-infected patients. By implication this means that more seriously ill and terminal patients are admitted to hospitals. This creates an enormous costly situation to deliver health services. Because of this, health authorities recommend a shift from hospital-based care to home-based care. Although the call to shift from curative hospital-based care to home-based care is clear, it is not well organised around strengthening the coordination of home-based care at community level.

The implementation of home-based care should be regarded as everybody's business if it is to be successful. It also needs political commitment. Diseases such as HIV/AIDS, cancer, malaria and TB can be combated if all sectors become actively involved in their prevention and control. To some extent, the deterioration in health status can be attributed to inadequacies in home-based care implementation. In order for home-based care to be successful, a discharge plan stipulating the process that should be followed should be drawn up and presented to the non-professional caregivers before patients are discharged from institutions. In many countries community organisations (CBOs) were developed that may include elements of HIV/AIDS-related networks and support focusing on home-based care issues.

Others focus on orphan support, the youth, women's needs, income generating activities and the care of HIV/AIDS- infected patients (Jackson 2002:226).

In order to overcome this problem, the Namibian government should formulate policies and guidelines on how to coordinate and implement home-based care at community level. It is estimated that more than 200,000 Namibians are living with HIV/AIDS (GRN 2003a: iii). This is at a time when health care costs are spiralling beyond the reach of average citizens and government. Most people will appreciate ways and means of reducing this expenditure (Kasanda 2003:6). Although one aspect of home-based care is support by skilled welfare officers, it is not possible in all circumstances especially not in the health district that was studied.

To send HIV/AIDS patients home for care may not always be the best solution, because the care of patients at home can become the complete responsibility of non-professional caregivers. In order for home-based care to be feasible, the hospital and health centre staff nearer to the non-professional caregivers may do home visits and provide a source of medical and social support. This makes it possible for non-professional caregivers to ask for advice if the patient is discharged from hospital when still sick and in need of nursing care. The other idea is based on palliative care, which is necessary. Doctors may prescribe some required medication (for example, an analgesic) for the patient to take at home. But this is only possible when a well-organised structure of home-based care is in place to provide such a service (Smith 2003).

Home-based care is a challenge. To care for patients at home is not a cheap alternative. It is costly because special food, medication, transport, aids (like dressing, cleansing solution [bleach] and disinfectants, and gloves) and other protective equipment may be needed. Families with limited finances may find it hard to meet these needs. Furthermore, it is clear that non-professional caregivers may be burdened physically, socially and mentally. Caring for a loved one with a terminal illness can have an impact on non-professional caregivers who become isolated from social interaction in the community. What makes the situation worse is that the role of the non-professional caregivers is not acknowledged formally by the health care system. Caring for a sick patient at home may bring conflict among members of the same family because some may sacrifice more than others.

Home-based care has many implications. According to Kasanda (2003:5), one of the implications is that the health care system does not have a comprehensive structure to offer home-based care and therefore the family has to assume responsibility for caring for terminally ill family members.

Home-based care is not an easy task because of the following barriers (Jackson 2002; UNAIDS 2000):

- shortage of equipment for home-based care (eg a home-based kit and medicine)
- the attitude of the HIV/AIDS-infected patient (eg aggression and frustration)
- lack of a cure and treatment

- lack of transport
- inadequate information, knowledge and skills on how to take care of patients and how to curb the spread of the disease
- long travelling distances
- lack of accessibility and affordability of antiretroviral drugs and absence of medicine for palliative treatment

In Namibia, at the moment, there is an urgent need to make home health care services as accessible as possible to everyone. If cooperation amongst non-professional caregivers and other sectors is encouraged, a more coordinated home-based care system can be provided to all Namibians truly reflecting its practice in remote communities. In other words, well coordinated home-based care requires a decentralisation of activities in order to reach the peripheral communities. Effective, suitable mechanisms for the integration and coordination of home-based care into the health care system should be identified and implemented with immediate effect. It is important for officials in the health care system to accommodate non-professional caregivers as partners in care. Non-professional caregivers at this stage should form part of the public health services and should be recognised as an important component of the broader health care team. Furthermore, their skills and experience should be used optimally to ensure maximum coverage and cost-effectiveness. If the non-professional caregivers are not incorporated into the health care system of this country, it is the community itself that will suffer.

2.3 The need for comprehensive home-based care

It is not possible to know when HIV transmission will occur (MOHSS 2004:107).

It is quite common for individuals in a relationship to receive different HIV test results, indicating one infected partner while the other partner is not infected. The difference in HIV test results is a problem in home-based care. Non-professional caregivers are not at a stage where they are ready to spread a message of safe sex and the use of a condom (Schwarz 2003:72). It is not easy for non-professional caregivers to discuss safe sex with partners because of cultural and traditional taboos. Men dominate sexual decision making. This includes the use of a condom.

Home-based care is not an easy task. In order to prevent the uninfected partner from getting HIV infection, behaviour changes are necessary to reduce the risk of transmission. In the Namibian context, especially in the northern part of the country, men decide when sex should take place. The cultural belief is that women have no right to refuse men sex. Culturally the mandate is to use power and therefore obligatory sex takes place in marriages and established relationships, possibly with infected partners (Shapumba et al 2004:9)

Non-professional caregivers face problems in caring for those who are infected with HIV and AIDS.

Prevention strategies for HIV/AIDS that are limited to “knowing the facts” and “becoming aware of the risk” have not succeeded where opportunities for transmission are embodied in the social and cultural organisation of communities. Bringing about behavioural change will require more than knowledge of the facts (UNAIDS 2000).

The problems can be addressed with compassion and by educating non-professional caregivers, provided that families and communities are seen as partners alongside them. Non-professional caregivers face problems in rendering home-based care in discordant conditions. Namibia's culture and traditions are an important cause of HIV and AIDS transmission. Social practice reveals considerable resistance to existing efforts to curb the disease (Shapumba et al 2004:9). It is not easy for non-professional caregivers to educate couples, and one may find that one partner is infected with HIV but he or she is unaware of it and appears healthy.

A study conducted in Thailand has shown that women do not have bargaining power to negotiate with their husbands regarding the use of condoms, because this could affect their family life adversely (Directory 2004:103).

A study conducted in the USA on HIV protection among women whose sex partners resist the use of condoms indicated that the primary exposure category for minority women is heterosexual contact; however, consistent use of condoms continues to be a challenge for many women.

The more effective preventive interventions focus on enhancing the negotiation skills women need to influence condom usage with their partners.

Risk behaviour for HIV was considered. The study results reveal that of the women who had made an attempt to use a condom and experienced resistance from their partners, 36% later succeeded in using a condom.

Findings from multivariate logistic regression analysis show that young women and those in monogamous relationships were more likely to have used condoms recently.
Women who continued to insist on using condoms following their partner’s expressed resistance were more likely to have used condoms recently. In addition, women who chose to abstain from sex in response to their partner’s resistance were also more likely to use condoms (Perrino, Fernandez, Bowen & Arheart 2004: 163).

According to Perrino et al (2004: 163) the results suggest that when women persist in their attempts to use condoms, successful condom usage is often possible even among women with resistant partners. These findings should help inform HIV prevention interventions for women, particularly in the areas of developing negotiation skills and effective safer sex communication with sex partners.

According to Iipinge et al (2004:1), there are many parts of the Commonwealth where unsafe sexual behaviour by men is condoned and where women remain victims of sexual violence and rape (Lima, Bauken, de Marco, Zuim & Malta 2004).
Non-professional caregivers who render home-based care are often unable to handle victims who face these problems.

Non-professional caregivers do their best to educate the community on the use of condoms and safe sex. But still, many husbands infect their wives who cannot say no to sex or cannot demand the use of a condom, even though women know or suspect that their spouses may be infected with the HIV (Shapumba et al 2004:9).

Caring for those who are infected remains an enormous national problem. Caring for the orphan is an integral part of home-based care. According to Ng'andu (2003:11), HIV and AIDS in Southern Africa is now the leading cause of death, outstripping other major killer diseases such as malaria and TB. Caring for the orphans that the pandemic has left behind compounds the task of home-based care (UNAIDS 2000:7).

Non-professional caregivers who are involved in home-based care are women, typically older women and teenage girls. Apart from their role of providing home-based care, these women have multi-faceted traditional responsibilities such as producing food and caring for their families. The burden of home-based care falls on the women in the family, with girls being taken out of school because eduction is no longer a priority (Phororo 2002:11). Because of home-based care, the girls who drop out of school to care for a sick parent or relative will have their opportunities for future employment compromised (Mallman 2003:10).

Home-based care provided by non-professional caregivers is not without problems. In some cultures and traditions, biological children are not allowed to see their parents naked (Mwangi 2001:2). The presence of an AIDS patient in the household entails a major reallocation of labour, away from tasks towards the care of the sick. And following the death of the breadwinner, especially the father or mother, household members are likely to split apart.

Comprehensive home-based care is needed to meet the basic needs of the infected patient and affected family members. Networking and organising support groups at community level provide effective home-based care. This assists with the burden of caring for increasing numbers of people infected with HIV/AIDS. The number of officially reported cases of HIV/AIDS infection in Namibia continues to increase at an alarming rate since the first case was reported in 1986. Because of the daily increase in the number of people infected with HIV/AIDS, there is also an increase in the number of people who develop full-blown AIDS (Iipinge et al 2004:6). This is an indication of why the number of people hospitalised for HIV/AIDS-related illnesses in Namibia increased from 355 in 1993 to 6,878 in 1999 (Kasanda 2003; Ng'andu 2003:11).

This number reveals that HIV/AIDS spread very rapidly despite efforts to combat and curb it. In 1999 a total of 14,866 newly infected cases were reported in Namibia, with 75,383 as cumulative infections (GRN 2001a:1). By 31 December 2000 a cumulative total of 82,886 were recorded and by 31 December 2003 another number of 136,068 cumulative HIV/AIDS cases was recorded by the Ministry of Health and Social Services. This indicates a continuous increase in the number of HIV-infected persons in

Namibia (GRN 2004a:1). In Southern Africa, HIV prevalence is maintaining alarmingly high levels among the general population. The driving factors, along with the circumstances and interventions that might inhibit the spread of the HIV should be better understood.

In Southern Africa factors that contribute to a very high vulnerability to HIV/AIDS infection (GRN 2004a:2) are:

- poverty and high levels of inequality in income
- mobility
- alcohol abuse
- inequality in status between men and women and in access to resources between rural populations and urban populations
- high percentage of female headed households with members living long distances from each other

In Namibia all the abovementioned factors contribute considerably to the spread of HIV/AIDS infection. Contributing factors (GRN 2004a:2) are:

- high mobility of individuals between different places in the country
- cross-border travel
- high prevalence of STIs
- widespread alcohol and substance abuse
- gender inequalities

Home-based care in Namibia will not be without its initial problems. This is due to the fact that there is still a high degree of denial among some community members who believe that the hospital is the best place where care should be provided. This is aggravated by former health services policy in Namibia, which focused on curative care. Historically, health services in Namibia were fragmented and paid little attention to the promotion of prevention care.

The community was seen as a passive recipient of health care. This view encouraged community members to believe much in hospital care. The passivity of the community should to be changed in order to fit in the provision of Primary Health Care if we are aiming at reaching all Namibians by 2000 and beyond (Iipinge 2001). This will only be possible with community involvement and participation.

It is also very important in order to avoid too high expectations from the family and non-professional caregivers, which could result in mistrust.

It is a known fact that there is neither cure nor vaccine for HIV/AIDS. Therefore, it is important that services to provide for the physical, emotional and spiritual needs of patients are rendered not only by health workers but also by the families and communities involved (GRN 2001b:10).

Despite the dramatic spread of HIV/AIDS from the initially diagnosed case in 1986, there is still no breakthrough in the development of treatments or vaccines.

Health education directed at modifying risk behaviour is still the only way whereby the disease can be contained.

An important lesson that has been recognised recently is that the problem of controlling the HIV is not just a question of controlling a virus; it involves tackling and putting the HIV into the broader context of sexuality and gender roles. Gender-based power relationships influence reproductive decision making among couples with HIV/AIDS. According to Ko (2004:163), women of reproductive age constitute one of the world’s fastest growing HIV/AIDS populations. In Taiwan this is fuelled by gender-based relationships and cultural influences on the reproductive decision-making process among married couples.

Gender-based power relationships have a significant influence on reproductive decision making and behaviour. A home-based care programme requires the involvement of voluntary services in meeting a patient’s needs in the home environment. This should include acquiring basic knowledge and skills, and how to reduce the risk of infection in caring for patients.

When it comes to the home-based care of PLWHA who need physical, emotional and spiritual care, it is vital to train family members and other non-professional caregivers.

People with HIV/AIDS can live healthy, productive and longer lives if proper care and support are provided.

Their immune systems can be strengthened and boosted by the proper administration of drugs, sufficient food and a balanced diet, and rest and exercise. Patients can cope much better in an environment that is conducive to acceptance and compassion. A caring positive attitude involves emotional support and it will also help PLWHA to overcome depression. It is therefore vital to build a caring and supportive community for HIV/AIDS–infected patients and their affected families. Hope and positive living boost the immune system in such a way that depression and stress are reduced. When caring for HIV/AIDS patients, there is no need to think that they will die. What is important is the hope that future advancements in medicine will find a solution to help these patients. It is a known fact that everyone will die sooner or later, and one hopes that it will be from old age. HIV/AIDS patients do have a chance to live longer (Jariyavilas et al 2003:62).

It is important to consider many factors in caring, but there are two crucial items that should especially be noted. Firstly, it is beneficial to know where HIV/AIDS comes from and, secondly, where it is going.

The view of the researcher in this regard is to raise awareness regarding the need to focus on the psychosocial aspects of HIV/AIDS in care. In home-based care one should consider that other curable diseases like TB (which can be vaccinated, treated and cured) are unlike the HIV/AIDS disease.

In this regard, terminally ill patients who have HIV/AIDS or other related chronic diseases like cancer need adequate pain relief, accessible and affordable drugs which are evenly and equally distributed, and financial support to counteract the loss of income of both patients and family caregivers (Sepulveda, Habiyambere, Amandua, Borok , Kikule, Mudanga, Ngoma & Bogale 2003:2).

Caring for HIV/AIDS patients requires commitment, dedication and patience. In the face of the cruellest pandemic humanity has ever known, there is a need for non-professional caregivers to be good role models of caring. A good role model is essential to keep hope alive in the infected patient that the pandemic will be defeated one day. This helps to enhance living positively. Living positively is about hope and improving quality of life. This means doing everything possible (physically, psychosocially and spiritually) to help the infected patient to live longer (FHI & USAID 2003:34).

Moreover, positive living inspires HIV/AIDS patients and their affected families. Positive living enhances acceptance and brings people closer by enabling them to live together and to support each other.

It also promotes happiness, love and a sense of belonging (Jariyavilas et al 2003:27). The love and loyalty that radiate from these dedicated people will result in treatment and caring that surpass their strenuous working conditions and limited resources. This reflects the true picture that today non-professional caregivers are at the forefront of care. They are responsible for the treatment of minor ailments in HIV/AIDS patients.

2.4 Provision of care to HIV/AIDS patients and their affected families

The care of a human being includes physical, psychosocial, economic and spiritual care. Maslow developed a theory of needs that places human needs in a hierarchy based on their relative importance for physical survival (Young et al 2003:96).

2.4.1 Physical care

According to Young et al (2003:97), physical needs are the factors required for the optimum physical and physiological function of the body. These include physiological processes, physical activities and adaptation processes -- all of which enable an individual to function with optimum efficiency and to respond appropriately to the environment. It also includes supportive activities of daily living such as bathing, feeding, mouth care/toilet care, prevention of and treating bedsores, and personal and environmental hygiene (GRN 2001b:10).

Adequate ventilation: Physical care should include providing an environment that is well-ventilated. It recognises the body's need for oxygen for tissue perfusion and the regulation of body temperature.

Food and nutrition: These are essential for body energy, repair of tissue and synthesis of energy. Human nutrition includes the process of feeding, digestion, absorption and metabolism of foodstuff in the body.

Elimination of waste products: Elimination refers to the expulsion of bodily wastes. This includes urine, faeces and vomit.

Maintenance of skin integrity: The skin is the body's first line of defence (Young et al 2003:98). It protects the underlying tissues and organs from micro-organisms. HIV/AIDS patients are prone to sores, erosion and eruption, which are all forms of skin breakdown that disrupt the integrity of the skin. The physical care of HIV/AIDS patients should not take place without considering the safety of non-professional caregivers. According to Jariyavilas et al (2003:113), emphasis should be placed on informing non-professional caregivers to avoid touching blood and other body secretions with their bare hands. Proper disinfection of contaminated items is highly recommended. All wounds should be handled by using protective gloves and clothing. The importance of hand washing and cutting nails short should be emphasised in order to maintain personal hygiene and to reduce cross-infection and co-infection.

Mobility and exercise: This depends on physical fitness, strength, neuromuscular function and musculoskeletal agility (Young et al 2003:98).

Hygiene: Hygiene refers to the science of health and preservation. In particular, the word refers to cleanliness, both of the individual and the environment. Individual hygiene needs are related to the maintenance of personal cleanliness and grooming. These factors are influenced by culture.

Environmental hygiene influences health. Many diseases such as upper respiratory infection and diarrhoea can be directly related to pollution. It is therefore necessary to maintain optimum environmental hygiene (Young et al 2003:98-99).

Comfort and rest: Comfort refers to a sense of ease and well-being. Physical comfort means not only the absence of pain; but also the position of the body, the temperature of the environment, and the absence of annoying distractions and stressful happenings. Rest refers to a state of physical inactivity, repose and relaxation. Sleeping and waking, and also factors that might cause restlessness, should be taken into account. Physical and emotional stress may interfere with an individual's ability to rest. Rest and sleep are essential for normal physical and psychological function in order to replenish energy and repair tissue (Young et al 2003:99).

Safety and security: The need for safety refers to the avoidance of physical injury and damage to the body. Safety in caring for HIV/AIDS patients is often compromised by a lack of accountability and transparency, which increases non-compliance with the use of protective measures and not adhering strictly to treatment. This leads to the risk of co-infection and opportunistic diseases (Jariyavilas et al 2003: 105).

Psychological safety refers to the feeling of being secure and knowing what to expect from the people around one. This includes being able to cope with events (Young et al 2003:99).

The psychological safety of HIV/AIDS patients means that they understand what is happening and trust that their best interests will be safeguarded. Their security is based on physical safety, which means adequate food, shelter and freedom from physical harm. Security is all-encompassing and it is a broader concept than safety. It includes having rights and safety under the law, for example human rights such as respect, support, and access to health care and educational facilities. Patients and their families are thereby assured of means with which to support themselves in society (Young et al 2003:99).

Sexual needs: These are influenced by a variety of factors, such as age, socio-cultural background, ethics, self-concept and physical fitness. It is important for patients who are infected with HIV/AIDS to be informed about safe sex and ways in which their sexual activities should be altered according to their health status.

This issue of safe sex requires serious attention in order to reduce spreading the infection to the uninfected partner (Young et al 2003:100).

Once physical care has been attended to, it is not difficult to address the social, economic and spiritual needs -- which constitute the burden that pervades the lives of infected individuals and their affected families.

2.4.2 **Psychosocial and socio-economic care**

Psychosocial needs refer to a variety of cognitive, emotional and interpersonal factors which enable individuals to adapt to the environment, form relationships with others and function successfully within a community. It includes adaptation, self-esteem, autonomy stimulation and communication (Young et al 2003:100-101). The patient, his or her family and other non-professional caregivers need counselling at home level in order to increase the coping mechanisms of the infected patients and their non-professional caregivers. Counselling enables the client and his or her family to accept the condition and to live more positively with HIV/AIDS. The socio-economic circumstances and cultural background of patients influence their nutritional needs. Psychosocial support and care increase community awareness about the availability of disability benefits, which includes government grants (GRN 2001b:10). Home care is a holistic concept that should incorporate the full spectrum of needs of patients, their affected families and the community in general. It should also address the needs of non-professional caregivers and children who will be orphaned (Jackson 2002:232).

2.4.3 **Spiritual care**

Human nature has a relationship dimension which encompasses the need to find meaning in life through a relationship with a supreme being. This means defining life values and a belief system, and relating to the self and to others within the framework of those life values, belief system or philosophies (Young et al 2003:102). Spiritual needs include grieving, religious expression and counselling (Young et al 2003:103).

The grieving process affects both the dying person and his or her significant other. An understanding of the process and how it can be facilitated helps one to cope with dying and death (Young et al 2003:245). By offering spiritual counselling and bereavement support, those who are affected are assisted in grieving and coping with the loss they experience. This includes provision of spiritual support like prayer, group meetings, and Bible study and reading.

2.5 **Challenges in the health care delivery system**

As in other parts of the world, the Onandjokwe Health District is having problems with the increase in the number of HIV/AIDS patients. The situation has led to overcrowded health facilities and it seems that health workers are unable to cope which leads to the option of home based care.

AIDS is a disease that is virtually invisible but confronts everyone with difficult questions about infection, illness and death. According to GRN (2002a:11), HIV prevalence among pregnant women in the Onandjokwe Health District is 27.3%. This shows that HIV/AIDS is the most challenging public health problem facing communities. It reduces the country’s scarce resources (such as human and financial resources), and capacities on which human security and development depend (GRN 2002a:1).

In 2002 it was estimated that the HIV/AIDS pandemic claimed more that 3 million lives worldwide. Five million people acquired the HIV, bringing the number of people living with the virus to 42 million (GRN 2002a:1; GRN 2004a:2). According to de Haro (2000:3), AIDS claims a life every 25 seconds. In Africa 2.4 million lives were cut short by the pandemic in 2002.

According to Iipinge et al (2004) and Shapumba et al (2004), migration and substance abuse expose Namibians to conditions and risk behaviour that are conducive to HIV infection. Temporary migrant workers are more likely to engage in risky sexual behaviour and substance abuse (Yang, Derlega & Luo 2004:160). Perrino et al (2004:163) indicate that substance abuse and personality disorders are predictors of sexual risk behaviour among persons with HIV/AIDS. Sexual risk taking is more prominent and is a continuing problem among a segment of the HIV-infected population whose unprotected sexual activity risks their own health and transmission of HIV to others (Lima et al 2004).

Traditional HIV/AIDS prevention efforts have stressed education and condom use, but have often ignored or underemphasised the importance of factors that may underlie sexual risk behaviour (Chernoff, Martin & Arns 2004:162). Chernoff et al indicate further that sexual risk behaviour among HIV-infected persons can be seen as a concomitant of substance abuse.

It is therefore important to note that prevention efforts that merely emphasise condom use will be ineffective without a strong component of alcohol and drug treatment. According to Singh, Singh & Singh (2004:581), alcohol is used as a stimulant and many victims use it before having sex with sex workers, leaving even less scope for safe sex.

HIV/AIDS is the most important public health problem facing Sub-Saharan Africa. According to Iipinge et al (2004:6), the number of HIV positive people in Sub-Saharan Africa is greater than in any other place on earth. Namibia forms part of this region and has not been spared from the frightening scenario. Again, another source indicates that from the majority of people with HIV about 95% live in developing countries.

This proportion is expected to grow further as infection rates continue to rise in countries with poverty, poor health systems and limited resources for prevention and care. This speeds up and fuels the spread of the virus (EECMY 2000:6).

Affordability of condoms and services is limited. Even if condoms are distributed free of charge by government health services, one should bear in mind that 50% of Namibian households are more than one hour’s walking distance from the nearest health facility. Lack of transport may restrict access (Schwarz 2003:71).

Although the Namibian health structure has been reformed to meet PHC criteria, the Namibian population is still confronted with many challenges. HIV/AIDS is ranked as the number one killer disease, followed by TB (Obeid, Mendelsohn, Lejars, Forster &

Brule 2001:39). Namibia is ranked among the top five countries that are most affected by HIV/AIDS, with a prevalence rate of 19.8% (GRN 2004b). HIV/AIDS is a major factor in the increase of hospitalisation. It is estimated that more than 200,000 Namibians are living with HIV/AIDS (GRN 2003a: iii; Kasanda 2003:1; Obeid et al 2001:45).

According to Shapumba et al (2004:4), Namibian youths have good knowledge about HIV/AIDS and measures to prevent HIV infection. But this knowledge is not transformed into practice.

HIV/AIDS does not affect Namibia only; it also poses challenges to other countries such as Thailand, where the first case was reported in 1984. The problem has resulted in serious social, economic and spiritual concerns. Human values and dignity are affected, causing many other problems such as human rights violations, discrimination and stigmatisation, and abandonment of orphans and affected children whose parents died of AIDS (Directory 2004:98).

The problem of the increasing number of HIV/AIDS patients forces people to look for better alternatives to conventional care. For many, the alternative is home-based care. Home-based care involves non-professional caregivers practicing as frontline helpers and the backbone that is necessary to complement quality care.

They (caregivers) volunteer as a result of the sincere call for community involvement and active participation, which in turn meets the needs of HIV/AIDS-infected patients and their families.

The HIV/AIDS pandemic marches hand in hand with TB. This is common in the Onandjokwe Health District, where more than half of the TB patients are also infected with HIV. This makes the TB disease more aggressive and difficult to shake off or control (Akwaake 2003:36). According to de Haro (2000), the most common opportunistic infection is TB. Two million people globally are infected with HIV annually and this number may double by 2010. Half of the AIDS patients in Sub-Saharan Africa die because of TB.

The fight against TB is inseparable from that against AIDS, since the two diseases are inseparable from each other and compound each other's effects.

The condition is worsening due to a lack of accountability and transparency, increasing non-compliance to the use of protective measures by non-professional caregivers and non-strict adherence to treatment regimes in the case of infected patients (Jariyavilas et al 2003:105; GRN 2002b). The sources further indicate that to reduce the risk of co-infection, non-professional caregivers should take proper care of physical wounds and should avoid touching blood with their bare hands.

It is imperative to inform HIV/AIDS patients and their families about personal hygiene such as washing hands, cutting nails, avoiding touching blood and body secretions, and avoiding cleaning wounds with bare hands (Jariyavilas et al 2003:113).

While there are those in society who display compassion and care for affected families and infected individuals, there are also many who still discriminate against victims of this disease. Most of the time, fear and lack of knowledge concerning the disease are the sources of this stigmatisation (Jariyavilas et al 2003).

The diagnosis and treatment of HIV/AIDS are associated with complex psychological effects, such as fear of the unknown, social isolation, impaired quality of life and the need to make remarkable lifestyle changes (John & Ndebbio 2002:59).

Diagnosis of HIV infection has a profound effect on the emotional and social well being of individuals and families. PLWHA experience fear of disability, dependence and death. They also experience stigmatisation and social isolation (Chege 2004:569). According to Jariyavilas et al (2003), the psychological effect is heavy due to lack of pre-counselling and post-counselling. This often leads to denial and non-acceptance of reality.

Health personnel who are responsible for educating and training non-professional caregivers in counselling skills are often ill-prepared and ill-equipped. Those who have special knowledge and skill in counselling HIV/AIDS-related problems are few and overworked. This is probably due to the many HIV/AIDS cases they have to attend to. And they have seen so many AIDS patients that they become desensitised to the disease and uncompassionate towards the victims whom they no longer see as being important (Jariyavilas et al 2003:88).

De Haro (2000:3) indicates that there is very restricted or non-existent access to care and extremely harsh social stigmatisation among Africans. These psychosocial problems can be devastating to persons living with AIDS. Stigmatisation in itself is enough to impair the community's willingness to provide the needed social support to HIV/AIDS patients. It impedes the will of individuals, families and the community to provide adequate social support to HIV/AIDS-infected patients.

A study in Thailand shows that PLWHA who developed symptoms were critically stigmatised and rejected by their families and communities. They did not have a place to resort to (Directory 2004:13).

Community-based care and support for PLWHA is therefore jeopardised by a lack of acceptance of these patients in the community. On the other side, identification of PLWHA is a tedious process and individuals, families and the community at large are not willing to disclose HIV/AIDS status (GRN 2002b; Thangaiah 2004:576).

Stigmatisation includes fear that stems from lack of knowledge, which results in the rejection of people with AIDS and sometimes their non-professional caregivers.

This can results in despair among non-professional caregivers and, ultimately, in the homelessness of AIDS-infected patients (Chola 2003:22; Jariyavilas et al 2003).

According to Jariyavilas et al (2003:17) and Mahoro, Mubangizi, Hitimana-Lukanika and Madra (2004:570), HIV/AIDS-infected patients and their affected families faced prejudice that took away their faith in the medical community. Discrimination and stigmatisation in the workplace and in schools are also experienced.

The disgust and prejudice PLWHA face also worsen the worry of infected patients and their families. The experience of stigmatisation reaches beyond HIV/AIDS patients and is also experienced by non-professional caregivers and families.

They are exposed to stigmatisation because they are living with HIV/AIDS patients, even though they may also care and provide assistance to patients with other terminal illness.

There is the problem of secondary stigmatisation. Non-professional caregivers, as members of a home-based care team, sometimes find themselves shunned by people who fear that a visit from them will reveal their painful secret to the neighbours. Even the wearing of gloves, especially in the home, has become a sensitive issue because of the association it has with AIDS (Mahatelo 2003:8).

According to Mudenda (2004:580), HIV/AIDS and malaria are two of the most widespread killer diseases in Zamibia today, resulting in a combined death rate of 80%. Both diseases weaken the people and the economy; therefore, eradicating or preventing both can improve the economy. HIV/AIDS is associated with stigmatisation and discrimination. The stigmatisation is so rife that 74% of 500 HIV/AIDS-infected respondents preferred calling their illness “malaria”, even when indicators/symptoms pointed to the contrary. This stigmatisation and discrimination are due to the fact that HIV/AIDS in Zambia is still associated with indiscriminate heterosexual vaginal intercourse. Shame and fear because of HIV/AIDS-related stigmatisation are common reason for declining voluntary testing, thus preventing many infected people from receiving much needed care and a support system.

A country in which denial flourishes is a country whose citizens are vulnerable to the silent spread of HIV until political figures and respected leaders speak out, thereby breaking the wall of silence. Unless this happens, there is little hope of mounting a vigorous broad-based effort against the pandemic (UNAIDS 2000:38).

It is natural to feel sad and tired when one is constantly exposed to suffering and loss while doing one’s job. Without support this can lead to burnout. When burnout occurs, people become despondent and lose their capacity for compassionate care. This leads to an inclination to develop a negative self-image and to become convinced that it is not possible to make a positive difference.

The needs of patients depend on the nature of the disease and its progress. In some instances the ability to provide self-care remains for a long time, or the debilitating disease extends over a long period of time with periods of remission that exhaust a patient’s will to care. In some cases the ability to care for one’s self depends on the extent of the debilitating disease. Furthermore, non-professional caregivers may act as agents to improve and complement the performance of daily activities (EECMY 2000:40).

When society/the community begin to understand AIDS better, the reaction to PLWHA will be more positive (Directory 2004:13). A study done in Ghana revealed that the need to receive free and quality information with regards to one’s sexual and reproductive health is always a privilege.
For many a youth there cannot be a place more worthy of equality education than a place with all the necessary facilities which promise confidentiality and sincerity (Ntreh, Agboste & Gbedzeha 2004:571).

Home-based care is a controversial issue. While it involves substantial benefits, it also has disadvantages which may lead to HIV/AIDS being neglected (Smith 2003:29). Patients are out of sight to health care services; their suffering is unseen, except for relatives and friends. Home-based care can simply be an excuse for governments to opt out of caring for people with HIV/AIDS-related diseases.

It is essential to remember that home-based care requires policy and guidance to function properly. Home-based care should be seen as a supplement to state medical care provision; not a replacement for it. To overcome these problems, any strategy adopted for home-based care should aim at improving care and social support for those infected and affected, through human resources development. It is against this background that the health authorities recognised the importance of community involvement and participation in fighting the challenges (GRN 2001a: 50).

HIV/AIDS challenges should be defeated by the health care system in collaboration with the support of home-based care via community involvement and participation. In order to do this, it is necessary to strengthen the efforts of the non-professional caregivers.

It would be wise not to wait until they are exhausted and new, appropriate community based interventions should be introduced to enhance their coping capacity (Uys & Cameron 2003: 28). It is important for females and males to participate and be involved in home-based care and to strengthen the support equally. According to Kavuma, Madraa, Onyango and Pariyo (2004:578), factors exist that influence male involvement in the home-based care programme. Among these are cultural, social and economic factors. In terms of decision making, men tend to take the upper hand. Community care intervention that included men as major partners have reported more success in the implementation of home-based care activities than those where men were not involved. According to Kavuma et al (2004:578), males are dominant breadwinners due to economic inequalities, while women are expected to be caretakers.

From a policy perspective, resources are limited and there is a need to conserve them. However, recognition of the need for inexpensive long-term care alternatives should not in any form shift the burden of care from the health care delivery system to the community. While there is a call for active community participation and involvement in home-based care, caution should be exercised to balance community home-based care coordination in all efforts (Nthabiseng 2001).

While community ownership goes some way towards sustaining a programme, there is no such thing as a sustainable free service even if everybody involved start as volunteers. It is therefore ideal to source funding before starting a service and raising the community's expectations. This is possible through community ownership, which ensures the continuity of a home-based care programme. Motivated communities validate and support non-professional caregivers in rendering care to patients irrespective of their suffering. Sustainable, affordable, equitable, accessible and effective home-based care should be an integral part of a country’s health and social services system. Achieving this requires coordinated actions at various levels of government (Smith 2003:30).

In a study conducted in India, it was found that women are more vulnerable to HIV infection.

Despite the increased vulnerability of women to HIV infection and the greater impact of HIV on women, there was no programme to address these issues on a broader level (Periasamy, Vijay & Augustine 2004:575).

Targeted intervention programmes for female sex workers and prevention of parent to child transmission (PPTCT) of HIV for women seeking antenatal care have resulted in increased stigmatisation. The existing situation demands that in order for women issues to be addressed, women have to either fall into the category of targeted intervention or PPTCT. There exists a very large gap between the understanding of the issues by policy makers and the real situation (Periasamy et al 2004:575).

2.6 Problems home-based caregivers face

2.6.1 Lack of education and limited training

The majority of families are always willing to take on the responsibility to care for dying relatives, but they need to gain essential knowledge and skills. The willingness and acceptance of non-professional caregivers to be involved in the provision of care and support depend on the information, training and education provided to them regarding the disease, its causes, prevention and the strategies implemented to reduce fear, stigmatisation, rejection and discrimination at all levels (GRN 2001b:1). Education is necessary where patients and their caregivers are unable to provide conventional care, but also lack information on how to perform tasks related to care (Young et al 2003:197).

Family members are most often the direct primary, non-professional caregivers for chronically ill patients at home. It is important that these people are adequately equipped with knowledge and skills to carry out tasks and get the emotional support they need when they feel powerless and hopeless. Non-professional caregivers, specifically women, are left uninformed and vulnerable to HIV infection because of lack of education. This is due to less empowerment of women to reduce risk of infection (UNAIDS 2000). Social and emotional support is essential in ensuring social adjustment, coping with chronic disease and improvement of quality of life.

Due to lack of knowledge and skills, patients and their families leave the hospital without being given adequate information on how to care of themselves or their patients at home. In some cases, non-professional caregivers are provided with limited information and support (Jariyavilas et al 2003:89).

According to Salmon (2002:12), HIV/AIDS is a burden that impacts on and threatens all sectors of society. Therefore it is vital that prior to discharging a patient for home-based care, health care providers should educate and train non-professional caregivers to understand the treatment and the personal care of their patients who are dying from HIV/AIDS. Health care workers has a great responsibility to respond to the training and educational needs of patients and non-professional caregivers regardless of the nature of the health problem. It is thus important for nurses to acquire skills in caring for patients and their families in the home setting. Non-professional caregivers should be instructed and guided on how to care for their AIDS patients before they leave the hospital.

Patients with chronic illness (including AIDS, TB and cancer) should not simply be discharged from the hospital without proper advice.

This indicates that in order for proper home-based care to take place, home-based caregivers should be informed about their patients' conditions. This will help them to offer home-based care smoothly and easily, provided that home-based care is well implemented, coordinated and supported at community level.

In Namibia over 90% of men and women indicated that they are willing to care for their relatives with HIV/AIDS in their own households a finding that should encourage home-based care programmes at community level (GRN 2003b:163). This is a positive indication that the Namibian community is accepting of and willing to comply with the chosen option of home-based care. Young et al (2003:201), indicate that it is important to teach patients about their own health problems prior to discharge.

Health education for the patient and his or her family is an integral part of discharge planning. The session should include the names of medications, their purpose and side-effects, and the importance of treatment regimen compliance. The issue of wound dressing, disposal of soiled materials and importance of hand washing should be emphasised (Young et al 2003: 99).

We should remind ourselves that HIV/AIDS and home-based care are two new concepts. Health caregivers, especially nurses, who take on the responsibility of training and educating non-professional caregivers and their sick patients are often ill-prepared regarding the HIV/AIDS disease. According to Mahatelo (2003:7), nurses and midwives have to take on a responsibility for which many of them are not trained. Many nurses obtained their qualifications before HIV/AIDS became known, so it was not incorporated in their training curriculum.

Nurses have not received special training on the HIV/AIDS disease, and it is not always easy for them to train and educate non-professional caregivers properly in issues related to HIV/AIDS. Nurses often lack adequate information, particularly in relation to HIV/AIDS disease prevention and care.

This is true for counselling education, where health staff has limited or inadequate knowledge and skills to meet the needs of non-professional caregivers. This is an indication that health staff lack counselling knowledge and skills, which are necessary to back up the physical, social and spiritual care of AIDS patients (Jariyavilas et al 2003:14). In order for non-professional caregivers to be actively involved in home-based care, the need of home-based caregivers to obtain the knowledge to act so that they do not become stagnant but change constantly with the dynamic nature of the disease should be recognised (Nthabiseng 2001: 1).

An update of information is therefore needed from time to time to keep abreast of new findings from conducted research. Apart from new sources of information from conducted research, there is ignorance, lack of information and knowledge about HIV/AIDS and how it spreads. Non-professional caregivers have limited knowledge concerning HIV/AIDS. Many non-professional caregivers are worried about their lack of knowledge and skills, because very few non-professional caregivers have obtained appropriate training.

They might be concerned about contracting the HIV/AIDS disease themselves even though HIV/AIDS is not contagious because it is not spread through normal everyday contact or from caring for a patient with AIDS, provided that the non-professional caregiver covers any cut or wound on the patient and is careful not to touch fresh blood or body secretions (Raen 2002:17).

Inadequate education and training for non-professional caregivers lead to failure in looking after HIV/AIDS patients adequately. Non-professional caregivers should be taught how to take care of HIV/AIDS-infected patients in order to detect and treat minor ailments. This knowledge and skills are important and applicable in caring for patients with persistent diarrhoea and TB, both of which are infectious.

Knowledge and skills of non-professional caregivers on self-care are also important. This is important in ensuring that non-professional caregivers remain healthy while promoting the capacity of self-care among the sick. At the same time, patients living with HIV/AIDS have a moral responsibility to protect others from infection.

HIV/AIDS-infected patients should cultivate a sense of hope and a will to live through self-care and determination.

2.6.2 **Lack of resources**

Home-based care is a collaborative effort. Historically, nurses, women and the female child have been responsible for provision of care in the home (Young et al 2003:204). Home-based care relies on two strengths that exist around the world: family and the community.

Patients with terminal illnesses have been cared for by families in the home since time immemorial, regardless of the cost. The sick had been cared for in the context of the family; children often took care of their elderly parents when they became adults (Nthabiseng 2001:1).

With the advent of HIV/AIDS a role reversal in caring has occurred. Parents find themselves in very difficult situations, caring for their dying children who are also the breadwinners of the family. Traditionally, caring and care giving in the home were mostly limited to the elderly, children and disabled persons and the number of those people was very low. The HIV/AIDS pandemic leads to many problems, which impede effective home-based care.

According to Jackson (2002:234-235), the basic challenges for effective home-based care, as a part of a wider health and welfare referral system, are:

- Coverage, which is essential. This means expanding coverage faster than the rate of the increasing number of HIV/AIDS patients.
- Economic cost, which is linked to the sustainability of the programme.
- Capacity for home-based care to support HIV prevention.
- Long term, for the care of children who are orphaned by the HIV/AIDS disease.
- Unmet family needs.
- Quality care, which requires provision of a basic minimum package of care.
- Providing gloves, bleach and medical supplies.
- Volunteers receiving structured training in nursing care and counselling skills.
- The home-based care programme should be able to access the health care supplies needed; sufficient food supplements required by patients, and financial assistance to poor patients and families.

Home-based care is not necessarily always a cheap alternative for household and community involvement. People who are living in poverty will find it very hard to care for their relatives at home and to maintain their health.

Therefore, it is important to determine how easy or difficult the task of home care will be, based on the resources that are available (Young et al 2003:203).

Scarcity of resources contributes towards feelings of hopelessness, depression and lack of empowerment among non-professional caregivers. The efforts of non-professional caregivers who work in an unsupportive environment sometimes end up in inherent stress.

Home-based care often forces non-professional caregivers to work under difficult conditions where the basic supplies of a home-based kit are lacking. According to Mabasa, Madondile, Nsaluba and Lusikisiki (2004:524), HIV prevention is the key to sustainable mass antiretroviral (ARV) intervention. Their study revealed that 98% of South-African adults are aware of the fact that unprotected sex leads to HIV/AIDS, yet condom usage is low and 1,500 new infections occur daily. This is often interpreted as knowledge that is not translating into practice. However, the real problem is a lack of availability of condoms and a complete absence of female condoms in health institutions. Some of the other equipment is also not available, such as protective gloves, bleach, disinfectants, and antiretroviral and analgesic drugs. This factor contributes to poor provision of quality care for patients in the home environment.

According to Kasanda (2003:9), poor quality care at home is the result of the interplay of factors such as lack of adequate resources, lack of information and skills, and debilitating illness.

The issue of limited human and financial resources should receive serious attention in order to make home-based care conducive and a feasible option in caring for HIV/AIDS patients. Non-professional caregivers caring for bedridden patients should be assisted despite scarce resources.

2.6.3 **Poverty**

According to Schwarz (2003:70), 75% of Namibians live under circumstances resulting from financial constraint. This affects all aspects of life, including the capacity for safe sexual behaviour. Poverty and financial constraints contribute to de-prioritisation of HIV/AIDS. Poverty fosters a general feeling of being powerless to shape one's own destiny in the face of adverse circumstances.

While depending on international, political, financial and technical support, lowering incidences of infection and mitigating the pandemic's impact should be a nationally driven agenda. In order for home-based care to be sustainable, effective and credible national responses require the persistent engagement of the highest levels of government (UNAIDS 2000). We know that AIDS is unique in its devastating impact on the social, economic and demographic underpinning of development (UNAIDS 2000:7). That is why home-based care should be coordinated as a single powerful national AIDS plan that involves a wide range of actors.

The needs of PLWHA extend far beyond drugs and health care. These patients need a lot of support to cope with the implications of the life-threatening disease.

The few surveys conducted on the impact of having family members with AIDS have shown that households suffer a dramatic decrease in income. Decreased income inevitably means fewer purchases and diminishing savings (UNAIDS 2000:27).

Rural families affected by HIV/AIDS experience a decrease in their agricultural output, which threatens their food security. Hunger is an increasing threat because food production has declined with the illness and death of agricultural workers. Famine is therefore a serious threat. UNAIDS estimated that families affected by AIDS could expect a 60% to 70% drop in their agricultural production and income. Since the HIV/AIDS disease is a chronic condition that lasts months and years, some of the care required will involve funds to supply food, drugs and transport to a health facility if the condition of the patient worsens and he or she becomes critically ill. Fields are left fallow because of a lack of farmers. This situation is compounded by the difficulties experienced by HIV positive and ailing Africans (de Haro 2000:6).

The HIV/AIDS pandemic is not confined to Namibia with its limited and/or lack of resources. It is a global problem: the very first AIDS cases were recorded in the United State of America in 1981 (de Haro 2000:6).

Home-based care is practised in many parts of the world and it becomes more popular because resources are decreasing and diseases like HIV/AIDS, cancer and TB continued to increase. Admission to hospital, expensive antiretroviral therapy (ART) and a poor economic climate worsened by escalating inflation rates have major implications for infected patients and other affected people.

Experience demonstrates that communities are often in the best position to take care of their own members. It is true that early discharge enables patients to be cared for at home by competent family members. However, it has become clear that non-professional caregivers at community level need an enabling environment, the tools and resources, to do so (Makhubela 2002). With the spread of the HIV/AIDS pandemic, more people are nursed at home. Hospitals can no longer accommodate the number of people that are serious ill from HIV/AIDS.

The disease is raging on and it is mature in many countries (Makhubela 2002:35). Non-professional caregivers should do all that is possible to lighten the burden for HIV/AIDS-infected patients. HIV/AIDS is a challenge to the socio-economic development of Namibia as a whole, including the health care system. The disease is robbing countries of scarce human and financial resources.

This is the capacity on which human security and development depend (Haoses 2003:38). A large part of the population is being lost to HIV/AIDS and this leads to massive economic and social costs.

At household level, HIV/AIDS has pushed even once thriving families into destitution because breadwinners have succumbed to the virus or have had to give up work to care for the sick (Ng'andu 2003:11).

Although HIV/AIDS is a disease that has generated much love, support and compassion in families (Jariyavilas et al 2003:27), it is a cruel disease that has taken many lives. HIV/AIDS overwhelms services, deepens poverty, cripples already fragile economies and plays havoc with population dynamics across the Sub-Saharan region (Ng'andu 2003: 11). The impact of HIV/AIDS is not only felt when household members die but from the onset of illness incomes have to be spent on purchasing medication and special food, thus affecting current consumption and spending. Home-based care of HIV/AIDS patients imposes considerable cost on patients and their families (Jariyavilas et al 2003). Other costs include financial, time and opportunity cost (or lost opportunities). There are also extra transport and labour costs. The impact of HIV/AIDS is more acute for some households (such as female-headed households). Since they are poorer than others and landless, they have very few options to fall back on.

HIV/AIDS has predominantly affected young adults who are usually the family income earners. The death of the breadwinner is the main cause of poverty and malnutrition because of the depletion of family members to farm arable lands and cattle.

AIDS pushes people deeper into the poverty because households lose their breadwinners, livelihood is compromised and savings are consumed by the cost of health care and funerals (Hormazd 2003: 8).

The impact of HIV/AIDS on the household is therefore enormous. It is clear that people with AIDS are less productive because they are unable to work for hours. The other people in the household have to re-allocate their time and priorities to spend more time in caring for the patient with HIV/AIDS. Home-based care is the solution that offer the feasible option for the majority of patients and non-professional caregivers at most stages of the disease -- not just the dying (Jackson 2002:232). Social support is essential to promote coping with extra mouths to feed because children have become orphans. Grandparents and elder siblings are incapable, in monetary terms, of bringing up HIV/AIDS orphans. Social support alleviates many consequences of HIV/AIDS diagnosis, repeated bouts of illness and ultimately death, including the impoverishment of families already near or below the poverty line (UNAIDS 2000:85).

What makes home-based care a demanding and exhausting activity is infected family members who return from urban areas to rural areas (UNAIDS 2000:27).

This adds a burden to scarce resources and increases the probability that a spouse or non-professional caregiver (or others in the rural community) will be infected. Families make great sacrifices to provide treatment, relief and comfort for a sick breadwinner (Directory 2004:49).

According to UNAIDS (2000:27), a common strategy in AIDS-affected households is to send one or more children away to extended family members to ensure that they are fed and cared for. Such extended family structures have been able to absorb some of the stress of increasing amounts of orphans, particularly in Africa. However, urbanisation and migration for labour, often across borders, are destroying that structure.

As the number of orphans grows and the number of potential non-professional caregivers shrinks, traditional coping mechanisms are stretched to breaking point. Households headed by orphans are becoming common in high prevalence countries (UNAIDS 2000: 27). Studies in Uganda have shown that following the death of one or both parents, the chance of orphans going to school is halved and those who go to school spend less time there than they had formerly. Furthermore, orphans face an increased risk of stunting and malnourishment (UNAIDS 2000: 27).

HIV/AIDS infection has a devastating effect on families and children have a limited chance of school attendance. Probable reasons are:

- lack of money for school fees
- lack of guidance because parents have been killed by HIV/AIDS

This makes orphaned children vulnerable to discrimination, stigmatisation and lack of emotional support (FHI and USAID 2003).

According to Phororo (2002:11), it has been observed that the death of an adult has a dramatic impact on the family structure and function, particularly where children are left to run the household. Children are unable to manage the remaining household assets and this result in food and security problems. Other identified challenges are that discontinuing their education becomes a better option for these children because they cannot afford the school fees and their survival becomes of the utmost importance.

According to de Haro (2000:46), 12 million children had lost either one or both parents, and 3 million children under the age of 15 years were infected at birth and were living with HIV. These unfortunate orphans are sometimes rejected and deprived of their heritage by their own families. Some involuntarily become heads of their families, in charge of caring for other siblings. Due to the absence of a structured support system, many people find themselves in extremely insecure situations. They become street children, forced to fend for themselves, and at risk of becoming delinquents and victims of sexual exploitation (de Haro 2000:46). Their education remains neglected because nobody is responsible for their care or come to their assistance.

In order to avoid the risk of stunting and malnourishment, non-professional caregivers (especially the involved family) need social and financial support; in order for home-based care to be successful, the care should involve interaction of support mechanism in the community. Some of the support mechanisms are rendered by the government, and non-governmental organisations assist PLWHA, their families and AIDS orphans (GRN 2001b:9).

An effective home-based care service depends on a continuum of care where the hospital, clinic and support services are linked with HIV/AIDS-infected patients and their families, including members of the wider community (Smith 2003: 30). Home-based care can only be effective in a properly mobilised community that is ready to assist others to maintain good health through availability of volunteers and community members.

The enhancement of community ownership goes a long way towards sustaining a programme because community ownership ensures the continuity of home-based care programmes. Motivated communities validate and support non-professional caregivers. Sustainable, affordable and effective home-based care should be an integral part of a country's health and social systems. Achieving this requires coordinated actions at various levels of government (Smith 2003:30).

Home-based care is a holistic concept that should incorporate the full needs of patients. It should address the needs of non-professional caregivers and children who are or will be orphaned (Jackson 2002: 232).

Providing home-based care can either bring family members closer together or drive them apart. Certainly, family dynamics are affected in the sense that looming disease becomes a physical, psychosocial and spiritual burden. Despite these challenges, home-based care should be developed and supported in the midst of poverty, inequality and discrimination. Apart from poverty, there are also other identified factors that influence the spread of HIV/AIDS. These factors are inequality in gender roles and relationships, and cultural and traditional practices. They influence HIV prevention methods negatively (Schwarz 2003).

According to Iipinge et al (2004) and Shapumba et al (2004:7), universal disparity exists between men and women regarding the social construction of gender roles, identities and decision making. Major decision making and resource management responsibilities are vested in men, even when joint activities are indicated.

Namibian cultures and traditions are an important source for the transmission of HIV/AIDS. Social practice reveals considerable resistance to existing efforts to curb the disease (Shapumba et al 2004:9). Relationships with infected partners can be discordant, especially in relationships where one partner is infected with HIV but is unaware of this and appears healthy. In such cases it is impossible to know when HIV transmission will occur (MOHSS 2004:107). It is quite common for individuals in couple relationships to receive different HIV test results indicating that one is infected while the other is not.

In order to protect the uninfected partner from HIV infection, behaviour changes are necessary to reduce the risk of transmission. This is possible if both partners had received voluntary counselling and testing (VCT) prior to meeting and engaging in sexual activities.

The other problem that non-professional home-based caregivers face is culture. It is not culturally accepted to talk openly about sexually related issues to young children. This is simply not part of the Namibia culture. The general observation is that an open talk between parents and their children is still considered taboo. A “thick wall” still exists between parents and their children when it comes to talking about matters pertaining to sex. This is worsened by a combination of the people’s religion and culture (Otaala 2000:30).

In order for home-based care to be successful, home-based caregivers should find a way how to break the message of safe sex during the activities involved in rendering home-based care. According to Shapumba et al (2004:5), communication between adults and youths on sexual matters (including HIV/AIDS) is restricted. Invariably a “top down” approach is still common or talking about sexual related issues is often non-existent. Home-based caregivers should give health education regarding safe sex, better options for income generating activities and women empowering. However, this creates a problem in many cases because of cultural taboos and religious beliefs.

A fair share of young males has transactional sex with partners who are mainly older working men (Schwarz 2003:7; Shapumba et al 2004:13-14). Economic dependency and age difference weaken girls' position in sexual decision making. Girls come into a position whereby they are made to feel that they "owe" their partners sex. The façade of a love relationship further complicates condom use negotiation.

It is important to remember that young people who are uninformed remain vulnerable to the risk of HIV/AIDS and other sexually transmitted infections. In order to overcome this problem, young people should be educated on risk behaviour. Risk reducing strategies (which include promoting safe sex, and the availability and equal distribution of condoms) should be made known to them. An emphasis should be placed on curbing the challenges of taboos and myths associated with sexuality and limited communication between non-professional caregivers, parents and children (GRN 2002c:1).

2.6.4 **Fear of not coping**

The fear of not coping among non-professional caregivers results from over-stretching traditional support systems due to the HIV pandemic which continues unabated. Non-professional caregivers may be frightened about giving emotional support to terminally ill patients. Non-professional caregivers probably experience psychological problems because they sometimes find it difficult to reconcile themselves with the emotions that engulf them when they lose patients to HIV/AIDS.

Young girls who are non-professional caregivers experience psychological trauma and depression as they watch parents and family members dying from AIDS. “Young girls are living with no hope and sense of despair, living in constant fear of losing a loved one” (Lindsey et al 2002:4).

Lack of political / government support. This means that “top down” commitment and support are required. According to du Pisani and Otaala (2001:v), politicians should become involved in educating the community about the danger of HIV/AIDS infection and the importance of prevention. Social pressure makes individuals vulnerable to HIV/AIDS. It encourages risky behaviour such as exchanging sex for food, and obtaining financial support and shelter in lieu of sex in a desperate bid to survive. Lack of moral values contributes to sexual risk behaviour. This is aggravated by alcohol and drug abuse, during which young people may indulge in casual sex and become infected.

The situation is worsened by gender inequality. A study conducted in Jakarta, Indonesia, reveals that the vast majority of young people remain uniformed about sex and STDs (Frisdiantiny & Rahmawati, (2004: 575). Although the majority have heard of AIDS, many do not know how HIV is spread and do not believe that they are at risk. This reveals that young people who are ignorant about HIV often do not protect themselves because they lack skills, support or the means to adopt safe behaviours (Frisdiantiny & Rahmanati 2004: 575).

According to Gruskin, Roseman and Fried (2004:573), at the global policy level there is increasing recognition of the connection between HIV/AIDS and violence against women. It has been observed that gender-based violence can increase vulnerability to HIV infection and that HIV infection can increase the risk of interpersonal violence. Women in general cannot exercise their right to refuse sexual relations and to claim the use of condoms. Some men have wrong beliefs that having sex with a young virgin will protect them against HIV/AIDS, and can cure the disease and other STDs (UNAIDS, UNICEF & USAID 2002; GRN 2002a; Singh et al 2004:581).

2.7 **Summary**

The chapter is an introduction of what is already known on home-based care and includes the theoretical framework used in the study. The researcher first gave an overview of home-based care. The necessity of comprehensive health care in home-based care provided to HIV and AIDS patients was also looked into. Some issues concerning basic needs were discussed in relationship to home-based care. These basic needs include physical needs with its component psychosocial, economic and spiritual cares. Challenges in the health care delivery system were explored. These challenges include overcrowded health facilities, overworked health workers, shortage of health caregivers and an increasing number of HIV/AIDS-infected patients. HIV and AIDS infection is a challenge that forces health authorities to look for better alternatives to cater for the needs of HIV/AIDS-infected patients.

Therefore, home-based care is often chosen as the best alternative. Home-based care has its own problems, especially the ones carried in poverty situations.

The HIV/AIDS disease is a serious challenge facing all Namibians. In order for HIV prevalence to drop, it requires a concerted effort from all sectors. Each person should take up the responsibility and become actively involved in the fight against the killer disease.

CHAPTER 3

RESEARCH METHOD

3.1 Introduction

This chapter describes how the study was conducted in the Onandjokwe Health District of the Oshikoto Region in Namibia. It describes the research design used in the study, including the pilot study, data collection (the population, sampling, etc), ethical considerations, and measures to ensure validity and reliability.

3.2 Research design and method

3.2.1 Research design

A quantitative, non-experimental design was used for this study. This approach was selected in order to provide a complete picture and understanding of how trained caregivers provide home-based care to HIV/AIDS patients (de Vos 1998:8).

The study is explorative, with the purpose of increasing insight and generating meaning regarding the home-based care that is given to HIV/AIDS patients.

It is also a descriptive study because it described the phenomenon as accurately as possible by using statistical, quantitative results from a sample representing the population (Mouton 1993:434). A contextual study involves conducting a study within a setting that includes the physical, social or economic environment. This study is contextual because it investigated the home-based care provided to HIV/AIDS patients by trained caregivers in the Onandjokwe Health District (Mouton 1993:133).

3.2.2 Research method

A research method can be defined as a systemic set of techniques and procedures that a researcher follows in order to collect and analyse data. In this study a survey was used to search for accurate information on the home-based care provided to HIV/AIDS-infected patients (Polit & Hungler 2001:186).

3.3 Population

The target population was all the trained caregivers caring for HIV and AIDS patients at home in the Onandjokwe Health District of the Oshikoto Region. The accessible population was one hundred and forty. All of them were registered with the Katonyala Home-based Care Organisation, Evangelical Lutheran Churches in Namibia AIDS Action (ELCIN), Tate Kalunga Mweneka Omukithi Gwo AIDS Moshigwana Shetu (TKMOAMS) and Catholic AIDS Action (CAA).

3.4 Sampling

The researcher used probability or random sampling, choosing the fishbowl technique. The reasons for choosing the probability sampling method were: each home-based caregiver had an equal chance to be selected; it permitted the researcher to estimate the sample errors and to reduce bias in the sample; it provided the researcher with the feasibility to generalise the research findings to the population. (Brink 1996:134). The researcher wrote the names of all one hundred and forty (140) home-based caregivers on slips of paper (NANASO 2002:18). The slips with the names on were placed into a container. The researcher then drew a slip from the container, noted the name, replaced the slip, shook the bowl and selected another name. The researcher replaced each name after each selection so that participants could have an equal and independent chance of being selected each time. If the researcher selected the name twice, she ignored the duplicate and repeated the process until the required sample was obtained (Brink 1996:136-7).

A list with the number of home-based caregivers per village and their addresses were obtained from Katonyala Home-based Care Programme, Onandjokwe Hospital, PHC and ELCIN.

Seventy (50%) of the respondents were selected due to logistical challenges. The respondents lived in villages and few of them had post boxes.
Because the questionnaires could not be posted, the researcher had to drive long distances to deliver the questionnaires and to collect them again.

3.5 Research instrument

A structured questionnaire was used as the research instrument. The questionnaire consisted of open-ended and closed questions. The questionnaire was designed to meet the following objectives: to describe the profile of home-based caregivers of HIV/AIDS-infected patients in the Onandjokwe Health District (see research questionnaire in annexure H, section A [questions1-9], section B [questions 10-18 and 25] and section C [questions52-54]); to determine the knowledge of home-based caregivers of HIV/AIDS patients in the Onandjokwe Health District about HIV and AIDS (see research questionnaire, section B: questions 19-24); to explain protective measures used by home-based caregivers of HIV and AIDS patients in the Onandjokwe Health District (see research questionnaire, section B: questions 30-40); to explore the personal experiences and coping strategies of home-based caregivers of HIV/AIDS-infected patients in the Onandjokwe Health District (see research questionnaire, section B: questions 26-29, 35, 41-48); and to identify the types of support home-based caregivers provide to HIV/AIDS-infected patients (see research questionnaire, section B [questions 49-51]; section C [questions 55-56] and section D [question 57]). The structured questionnaire (annexure H) was designed to elicit information from the subjects through self-completion of the questionnaire.

The questionnaire had the following uses or advantages:

- It identified and explored events and meanings.
- It explored and tested relationships.
- It validated information.

The following types of closed questions were used in the study:

- Dichotomous items (Polit & Hungler 2001: 267), are items that required the respondent to make a choice between two responses or alternatives.
- Multiple-choice questions that offered more than two possible responses (Polit & Hungler 1999). Closed questions limited the scope of the study to the respondents (Polit & Hungler 2001:267).

The researcher compiled the questions from the available literature (books, journals and the Internet) with the help of colleagues who had experience in research design. The questionnaire consisted of four sections: sections A, B, C and D.

Sections A, B and C: These three sections consisted of 21 questions that dealt with the profile of home-based caregivers.

Section B: This section consisted of six questions that dealt with home-based caregivers' knowledge about HIV and AIDS; 11 questions that dealt with the protective measures used by home-based caregivers; and 13 questions that dealt with the personal experiences and coping strategies of home-based caregivers.

Sections B, C and D: These sections dealt with the types of support provided to HIV and AIDS patients.

The questionnaire consisted of a total number of 28 closed questions and 29 open-ended questions. Guidelines and instructions were given on how to complete the questionnaire.

3.6 **Measures to ensure validity and reliability**

3.6.1 **Reliability**

The researcher conducted a pilot study in the Oshana Health District to test the feasibility of the questionnaire. The information obtained was used to improve the research instrument (Polit & Hungler 1999:44). This was done because any research instrument should be tested for reliability and validity. Ten non-professional caregivers were used in the pilot study, but they were excluded from the sample of the population.

Reliability assists the researcher to identify difficulties in the method and materials used, and to investigate the accuracy and appropriateness of the questionnaire (Bless & Higson-Smith 2000:129). Pitfalls and errors that may prove costly in the study are identified and avoided. In this study some questions relating to physical and spiritual care which were previously omitted were later added. Moreover, some questions that were placed in wrong sections were moved to the appropriate sections. The questions were also cross-checked for any ambiguities or repetition. All the minor problems that were identified were corrected and the questions were refined.

3.6.2 **Validity**

The structured questionnaire contained questions relating to the important aspects covered in the literature review. In order to ensure content validity, the opinions and suggestions of expert health professionals who reviewed the questionnaire were incorporated (Brink 1996:167). The researcher also consulted an English language expert to ensure readability and clarity.

3.7 **Data collection**

The questionnaires were assigned numbers, which corresponded with the numbers assigned to the draw names of the respondents.

The researcher personally distributed the 70 questionnaires to the respondents. The respondents were given three weeks in which to complete the questionnaires. However, some of the respondents failed to complete their questionnaires within the provided timeframe and they were therefore given another three days to complete the questionnaires, after which provision was made to collect the completed questionnaires. All 70 questionnaires were returned.

3.8 **Ethical considerations**

Permission to conduct the study was sought from the following institutions and authorities:

- University of Namibia, Senate Committee
- Permanent Secretary of the Ministry of Health and Social Services
- Primary Health Care District Supervisor of the Onandjokwe Health District
- Counsellor of Oniipa Constituency and Governor of Oshikoto Region (see annexures D, E, F and G for the letters requesting and granting permission to conduct the research).

During the study and throughout the research process, the following ethical aspects were taken into consideration. Participants were given the choice to withdraw from the study at any given time. This ensured informed consent and voluntary participation. In other words: nobody was forced to provide information against their will.

Confidentiality and anonymity were ensured because no names or other personal details were provided on the questionnaires. Confidentiality was further ensured because the information was maintained in privacy and kept private. The researcher, her supervisor and the Permanent Secretary of the MOHSS had access to the information. No information was disclosed or discussed with any irrelevant authority or third party. However, the findings of the research will be published in future with the permission granted by MOHSS for the benefit of improving home-based care.

3.9 Summary

This chapter describes how the research was conducted. It covered the research design, population, sampling, research instrument, measures taken to ensure reliability and validity, data collection and ethical considerations. The structure of the questionnaire and the technique of collecting data were explained.

CHAPTER 4

ANALYSIS AND PRESENTATION OF DATA

4.1 Introduction

This chapter deals with the analyses and interpretation of the collected data. The data was analysed manually and by the computer programme Statistical Package for Social Science (SPSS), version 10, which is available at the University of Namibia. The data were analysed with the assistance of a statistician. Responses to the questionnaire were fully displayed. This chapter answers the research questions outlined in chapter 1 (see section 1.5). The descriptive method of quantitative data analysis was used, and the data was presented in the form of statistical frequency tables and graphics. The descriptive method assisted in organising and summarising the research findings.

4.2 Profile of home-based caregivers

4.2.1 Sex of respondents

Female non-professional caregivers made up the largest part of the research participants: 62 (88.6%) of the respondents were female compared to the eight (11.4%) male respondents.

4.2.2. **Age of respondents**

The ages of the respondents ranged between 15 years to 66 years, and were grouped into intervals of 16 years. The largest number of respondents amounted to 29 (41.4%) and was in the age group of 32 to 48 years. The respondents between 15 and 31 years amounted to 19 (27.1%). The rest of the respondents were in the age group between 49 and 65 years, and amounted to 15 (21.4%). The age group 66 years and above had three (4.3%) respondents, and four (5.7%) respondents who failed to indicate their age group were categorised as missing data.

Table 4.1: Age of respondents (N = 70)

Age of respondent	**Number**	**Percentage**
15 – 31	19	27.1
32 – 48	29	41.4
49 – 65	15	21.4
66+	3	4.3
Did not indicate	4	5.7
Total	**70**	**100**

4.2.2 Marital status of respondents

The research findings revealed that 33 (47.1%) respondents were married, 22 (31.4%) were single, 13 (18.6%) were widowed, one (1.4%) was divorced/separated and one (1.4%) did not indicate his or her marital status.

Table 4.2: Marital status of respondents (N = 70)

Marital status	**Number**	**Percentage**
Single	22	31.4
Married	33	47.1
Widowed	13	18.6
Divorced/separated	1	1.4
Did not indicate	1	1.4
Total	**70**	**100**

4.2.4 **Highest level of education of respondents**

The research findings revealed that all the respondents had at least primary school education and 40 (57.1%) also had secondary school education.

Table 4.3: Level of education of respondents (N = 70)

Highest level of education	**Frequency**	**Percentage**
Primary school education	30	42.9
Secondary school education	40	57.1
Total	**70**	**100**

4.2.5 **Religious affiliation of respondents**

The research findings indicated that 68 (97.1%) respondents had religious affiliation. Only two (2.9%) respondents indicated that they did not belong to any religion.

4.2.6 **Types of religious affiliation of home-based caregivers**

The data showed that the majority of respondents (64, which is 91.4%) belonged to the Lutheran Church. Only two respondents (2.9%) belonged to the Roman Catholic and the Anglican Church respectively. Two (2.9%) respondents did not answer this question.

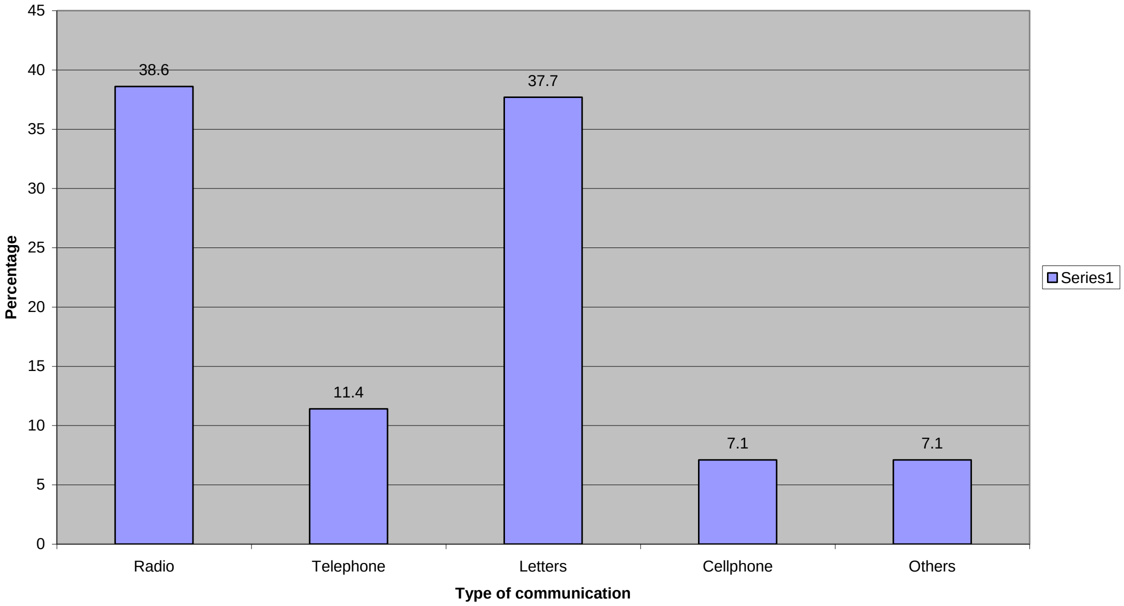
4.2.7 **Accommodation**

The data indicated that 68 (97.1%) respondents lived in traditional houses. One respondent (1.4%) lived in a brick house and one (1.4%) respondent lived in an informal settlement.

4.2.8 **Means of communication**

The research findings revealed that 27 (38.6%) respondents used the radio to communicate their needs to NGOs and health care facilities; 25 (37.7%) respondents used letters as a means of communication; eight (11.4%) respondents used telephones; and five (7.1%) respondents used cell-phones. The remaining five (7.1%) respondents indicated other methods of communication (eg church announcements, community meetings and face-to-face communication).

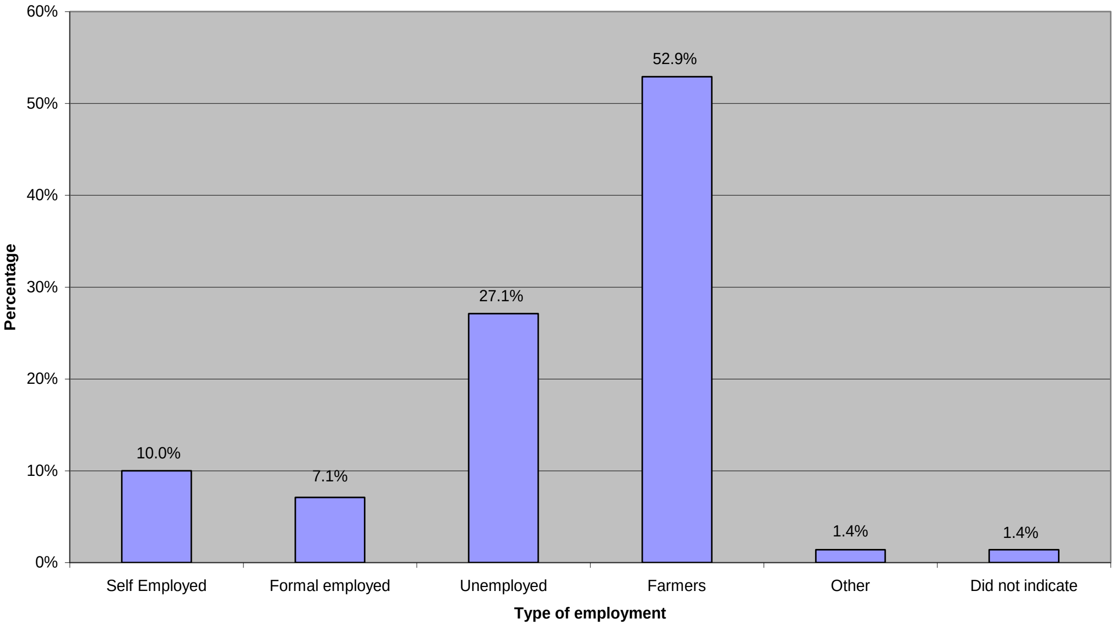
Figure 4.1 Means of Communication (N = 70)



4.2.9 **Employment status**

The data showed that 37 (52.9%) respondents were farmers and 19 (27.1%) respondents indicated that they were unemployed. Five (7.1%) respondents were formally employed; seven (10.0%) respondents indicated that they were self-employed; one (1.4%) respondent indicated another source of income such as old age pension; and one (1.4%) respondent did not indicate anything.

Figure 4.2: Employment status of the respondents (N = 70)



4.2.10 **Number of people living in the household**

The data showed that 17 (24.3%) respondents indicated five people or less in their households; 24 (34.3%) respondents indicated six to 10 people; 25 (35.7%) respondents indicated 11 to 15 people; and two (2.9%) respondents indicated 16 to 20 people. The other two (2.9%) respondents have 21 people and above in their households.

Table 4.4: Number of people living in household N = 70

Number of people	**Frequency**	**Percentage**
1-5	17	24.3
6-10	24	34.3
11-15	25	35.7
16-20	2	2.9
21 and above	2	2.9
Total	**70**	**100**

4.2.11 **Children under five years**

The largest number of respondents (36 or 51.4%) had one to three children under the age of five years in their households; 19 (27.1%) respondents indicated that they did not have children under five years in their households; eight (11.4%) respondents indicated that they had four to six children under five years; three (4.3%) respondents indicated that they had seven to nine children under five years; and another three (4.3%) indicated 10 to 12 children younger than five years in their households. The last respondent (1.4%) indicated 13 and above children in his or her household.

Table 4.5: Children under five years living in the household N = 70

Children under five years	**Frequency**	**Percentage**
None	19	27.1
1 – 3	36	51.4
4 – 6	8	11.4
7 – 9	3	4.3
10 – 12	3	4.3
13 and above	1	1.4
Total	**70**	**100**

4.2.12 **Children between six and 18 years**

The data showed that 13 (18.6%) respondents indicated that they had no children between six and 18 years in their households; 21 (30.0%) indicated that they had one to two children between six and 18 years in their households; 13 (18.6%) indicated that they had three to four children between six and 18 years in their households; 12 (17.1%) respondents indicated that they had five to six children between six and 18 years in their households; four (5.7%) respondents indicated that they had seven to eight children between six and 18 years in their households; and five (7.1%) respondents indicated that they had nine and more children between six and 18 years in their households.

Two (2.9%) respondents did not indicate whether or not they had children between six and 18 years in their households.

Table 4.6: Number of children between six and 18 years (N = 70)

Number of children between six and 18 years	**Frequency**	**Percentage**
None	13	18.6
1 – 2	21	30.0
3 – 4	13	18.6
5 – 6	12	17.1
7 – 8	4	5.7
9 and above	5	7.1
Did not indicate	2	2.9
Total	**70**	**100**

4.2.13 **Employed people**

The data showed that 27 (38.6%) respondents indicated that no-one in their households were employed; 32 (45.7%) respondents indicated that they had one to two members who were employed, while six (8.6%) respondents had three to four household members who worked. Only one (1.4%) respondent had more than four people in his or her household who worked. Four (5.7%) respondents did not indicate anything.

4.2.14 **Monthly salary per person**

The data showed that 22 (31.4%) respondents indicated that their family members received a monthly salary of less than N$500.00; 16 (22.9%) respondents indicated that the monthly salary per person in their households amounted to between N$501.00 and N$1999.00; 14 (20.0%) respondents indicated N$2000.00 to N$2999.00; and 14 (20.0%) respondents indicated that none of their household members earned a salary. The four respondents (5.7%) who did not respond to this question either did not know the salary figures of their household members or nobody in their households worked for a salary.

Table 4.7: Monthly salary per person (N = 70)

Monthly salary	**Frequency**	**Percentage**
<N$ 500.00	22	31.4
N$ 501.00 – N$ 1999.00	16	22.9
N$ 2000.00 – N$ 2999.00	14	20.0
No salary	14	20.0
Did not indicate	4	5.7
Total	**70**	**100**

4.2.15 **Income generating activities**

The data showed that 37 (52.9%) respondents indicated that they obtained income from farm products; nine (12.9%) respondents engaged in informal selling; 14 (20.0%) respondents indicated that they generated income from their cuca-shops[1] and eight (11.4%) respondents indicated that they sold hand-made baskets, clay pots and home-made brew like okatokele, ontaku, etc in order to survive. It can be assumed that the sheer burden of providing care does not allow non-professional caregivers opportunities to engage in income generating activities that are critical for their own survival and livelihood. Two (2.9%) respondents indicated that they owned local stores.

4.2.16 **Mode of transport frequently used by home-based caregivers**

The largest number of respondents (50 or 71.4%) indicated that their most frequent method of getting from place to place is walking. Three (4.3%) respondents indicated that they used public transport to reach patients' houses; only one (1.4%) respondent used a other means of transport such as donkey cart, own car or bicycle. Three (4.3%) of the respondents did not indicate anything and 13 (18.6%) respondents lived with the patients in the same households.

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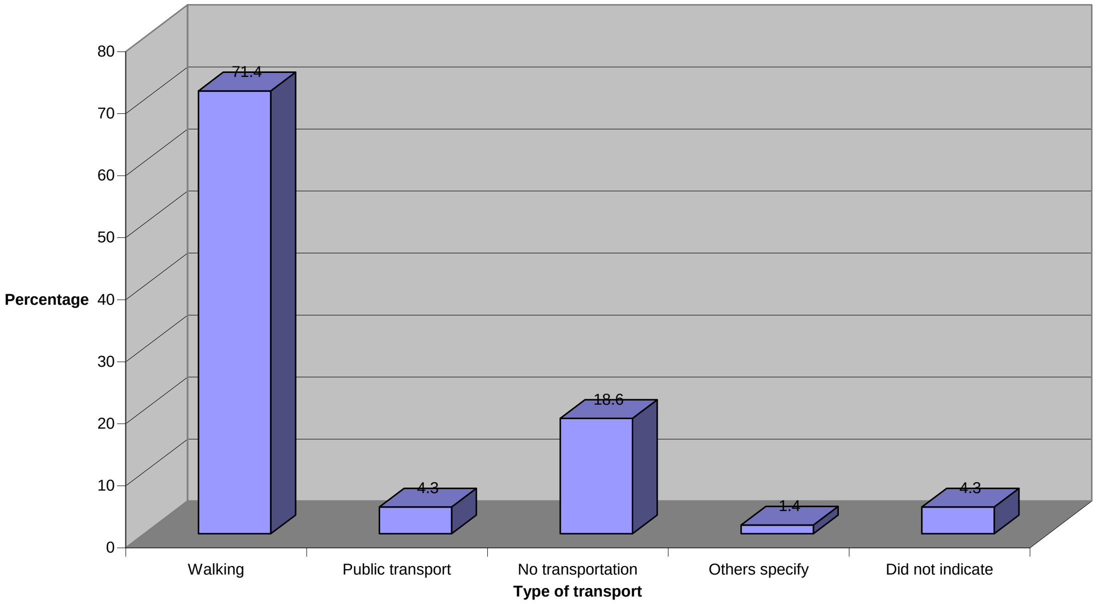
[1] Cuca-shops is a small local shebeen were cool drinks and beers are sold.

Figure 4.3: Mode of transport frequently used by home-based care providers



4.2.17 **Means of transport to health facilities**

The data indicated that 35 (50.0%) respondents used public transport; four (5.7%) respondents used their own car to commute to the health facilities; 19 (27.0%) respondents used donkey carts as a means of transport to get to a healthy facility; and 11 (15.7%) respondents used other means such as walking, horse riding or travelling by “oshilei” (an animal drawn sledge) and bicycle. One (1.4%) respondent did not indicate anything.

Table 4.8: Means of transport to health facilities (N = 70)

Means of transport to health facilities	**Frequency**	**Percentage**
Public transport	35	50.0
Own car	4	5.7
Donkey cart	19	27.0
Other (specify)	11	15.7
Did not indicate	1	1.4
Total	**70**	**100**

4.2.18 Distance to health facilities

The data showed that 12 (17.1%) respondents travelled less than 5km to reach health facilities, while nine (12.9%) respondents travelled 5km to 9km to reach health facilities. Seventeen (24.3%) respondents travelled 10km to 14km; 15 (21.4%) respondents travelled 15km to 19km; 11 (15.7%) respondents travelled 20km to 24km; and six (8.6%) respondents travelled more than 25km to reach health facilities.

Table 4.9: Distance to health facilities (N = 70)

Distance to health facilities (km)	**Frequency**	**Percentage**
< 5	12	17.1
5 – 9	9	12.9
10 – 14	17	24.3
15 - 19	15	21.4
20 - 24	11	15.7
> 25	6	8.6
Total	**70**	**100**

4.2.19 **Training in home-based care**

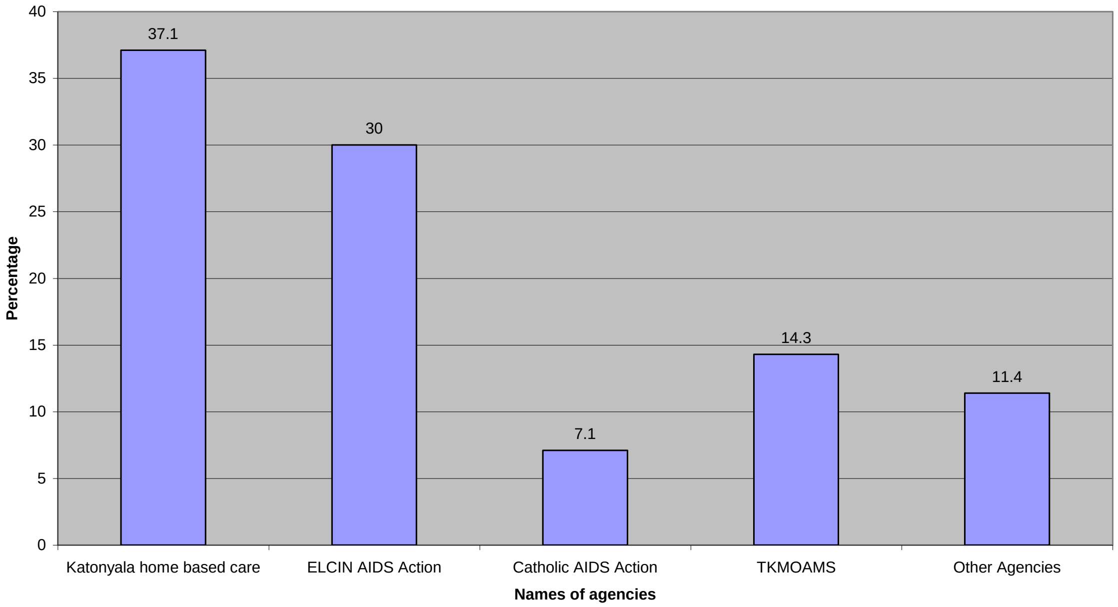
Nearly all the 69 (98.6%) respondents indicated that they were trained in home-based care, while one (1.4%) respondent did not respond to this item.

4.2.20 **Names of training agencies**

The data showed that 26 (37.1%) respondents indicated that they were trained by Katonyala Home-based Care; 21 (30.0%) respondents were trained by ELCIN with the support of TKMOAMS; five (7.1%) respondents were trained by Catholic AIDS Action; 10 (14.3%) respondents were trained by TKMOAMS[1]. The remaining eight (11.4%) respondents were trained by other agencies such as Lifeline/Childline, and Lironga Eparu and Individuals.

TKMOAMS[1] is an acronym of an Oshiwambo phrase meaning "God protect our nation from this disease AIDS".

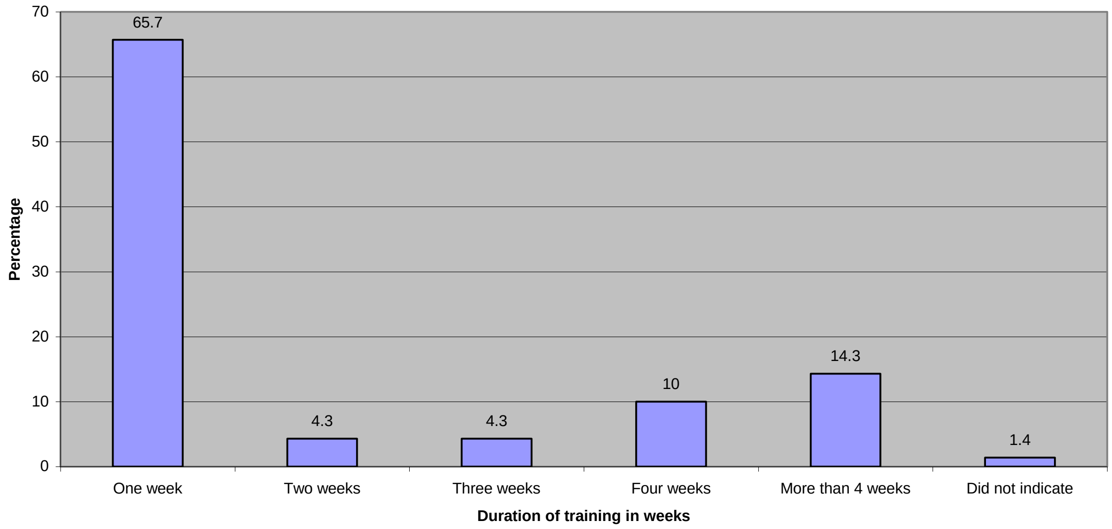
Figure 4.4: Names of Training Agencies (N = 70)



4.2.21 **Duration of training**

The data showed that 46 (65.7%) respondents indicated that they had trained for one week; three (4.3%) respondents trained two weeks of training; three (4.3%) respondents trained for three weeks; seven (10.0%) respondents trained for four weeks; and 10 (14.3%) trained for more than four weeks. One (1.4%) person did not indicate anything. (The results are depicted in figure 4.5.)

Figure 4.5: Duration of training (N = 70)



4.3 Home-based caregivers' knowledge about HIV and AIDS

4.3.1 Knowledge about HIV

The research findings revealed that 19 (27.1%) respondents had adequate knowledge of HIV, with the majority of 44 (62.9%) respondents only indicating that HIV is a virus. Five (7.1%) respondents supplied irrelevant information (which means that they possessed no knowledge of HIV) and two (2.9%) respondents did not give any answer.

4.3.2 Knowledge about AIDS

The research findings showed that 20 (28.6%) respondents had a good knowledge about AIDS. The largest number of 48 (68.6%) respondents supplied partial explanations about AIDS. Two (2.9) respondents did not indicate anything.

4.3.3 Modes of spread

The data showed that 20 (28.6%) respondents mentioned all the possible ways of how HIV and AIDS are spread (ie sexual intercourse; from infected mother to her unborn child; breastfeeding; use of contaminated needles, syringes and equipment; sharing contaminated sharp instruments such as razors, blades or other skin piercing items; and blood transfusion). Twenty-nine (41.4%) respondents indicated sexual intercourse as the major mode of spreading HIV and AIDS without mentioning other modes; 12 (17.1%) respondents indicated three possible modes; and nine (12.9%) respondents mention two modes of spread.

Table 4.10: Modes of spread (N = 70)

Modes of spread mentioned by respondents	**Frequency**	**Percentage**
All the possible ways of spreading the disease	20	28.6
Three modes of spread	12	17.1
Two modes of spread	9	12.9
One mode of spread	29	41.4
Total	**70**	**100**

4.3.4 Signs of HIV/AIDS

The data showed that 54 (77.2%) respondents indicated one of the major signs of HIV/AIDS with two or three minor signs, while 12 (17.1%) respondents failed to differentiate between major signs and minor signs.

Four (5.7%) respondents indicated clearly that HIV/AIDS signs are difficult to identify, and the only way of diagnosing is through blood testing and laboratory confirmation.

4.3.5 **Prevention of HIV/AIDS**

The data showed that 54 (77.1%) respondents indicated that HIV and AIDS infection can be prevented by abstaining from sex; 44 (62.9%) respondents mentioned that avoiding having unprotected sex and the use of condoms can prevent HIV and AIDS infection; and 38 (54.3%) respondents mentioned avoiding having multiple partners. Thirty-three (47.1%) respondents indicated that being faithful to one partner; avoiding donating blood for blood transfusions if HIV and AIDS infection is suspected (especially if the blood is not screened for HIV infection); avoiding sharing used instruments such as syringes, needles and razors; avoiding touching body fluids such as blood, semen and vaginal secretions can prevent infection. Two (2.9%) respondents did not indicate anything.

4.3.6 **The cure for HIV/AIDS**

The research findings revealed that 63 (90.0%) respondents indicated that there is no cure for HIV/AIDS, while four (5.7%) respondents believed there was a cure for HIV/AIDS. Three (4.3%) respondents did not indicate anything.

4.4 Protective measures used by home-based caregivers

4.4.1 Use of protective measures

The data showed that 65 (92.9%) respondents indicated that they used protective measures when caring for HIV/AIDS-infected patients; four (5.7%) respondents did not use protective measures; and one (1.4%) respondent did not indicate anything.

Table 4.11: Use of protective measures (N = 70)

Do you use protective measures?	Frequency	Percentage
Yes	65	92.9
No	4	5.7
Did not indicate	1	1.4
Total	**70**	**100**

4.4.2 Types of protective measures

The data showed that 57 (81.4%) respondents indicated that they used gloves depending on the availability thereof; 35 (50.0%) respondents indicated that they used plastic bags; 15 (21.4%) respondents used plastic aprons; four (5.7%) respondents indicated that they used face masks; and five (7.1%) respondents indicated that they sometimes used napkins and linen-savers. Four (5.7%) respondents did not respond to this question.

4.4.3 **Reasons for not using protective measures**

Among the respondents who did not use protective measures, three (4.3%) indicated that they did not use protective measure because none were available or at their disposal; two (2.9%) respondents indicated that there was no need for protective measures because their patients have no sores, wounds and infectious diseases like TB. One (1.4%) respondent did not indicate anything.

4.4.4 **Frequency of usage of protective measures**

The data showed that 29 (41.4%) respondents indicated that they always used protective measures and 35 (50.0%) respondents indicated that they sometimes used protective measures. Six (8.6%) respondents did not respond to this item.

Table 4.12: Frequency of usage of protective measure (N = 64)

Variables	**Frequency**	**Percentage**
Always	29	41.4
Sometimes	35	50.0
Did not indicate	6	8.6
Total	**70**	**100**

4.4.5 **Reasons for using protective measures**

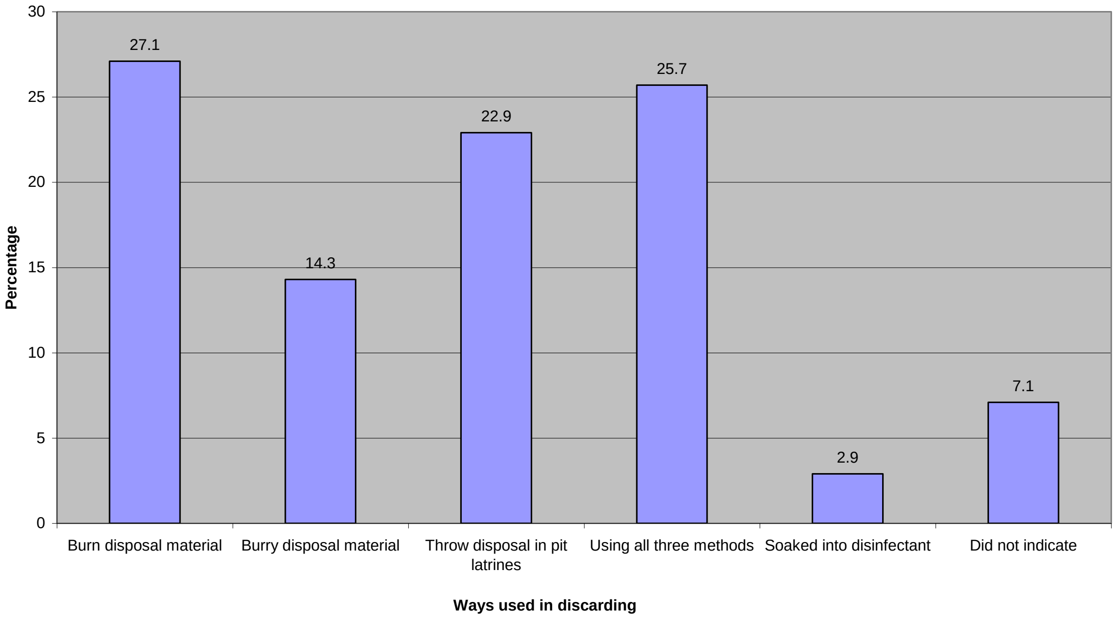
The data showed that 19 (27.1%) respondents indicated that they used protective measures to prevent contamination, co-infection and cross infection; and 46 (65.7%)

respondents indicated that they used protective measures to protect them from contamination and infection. Five (7.1%) respondents did not indicate anything.

4.4.6 **Ways of handling and discarding soiled materials and items**

The data showed that 19 (27.1%) respondents indicated that they burned materials that are for single use and washed washable materials with water, wore protective gloves or used carry bags and plastic containers; 10 (14.3%) respondents indicated that they buried disposable items and washed washable materials for re-use; 16 (22.9%) respondents revealed that they threw soiled items in pit latrines; 18 (25.7%) respondents threw soiled materials into pit latrines or burned it, washed washable materials for re-use, soaked soiled linen in Savlon or Dettol before washing it in warm water, and covered their hands with gloves or plastic containers during washing. Two (2.9%) respondents indicated that they soaked the soiled item in a disinfectant before washing it. Five (7.1%) respondents did not indicate anything.

Figure 4.6: Ways of handling and discarding soiled materials / items



4.4.7 **Owning a home-based care kit**

The data revealed that 36 (51.4%) respondents have home-based care kits and 33 (47.1%) respondents do not have home-based care kits. One (1.4%) respondent did not indicate anything.

4.4.8 **Utilisation of a home-based care kit**

The data showed that 28 (40.0%) respondents indicated that they used a home-based care kit as a first aid tool and three (4.3%) respondents indicated they did not know about the home-based care kit. Thirty-nine (55.7%) respondents did not indicate anything.

4.4.9 Items used if home-based caregivers do not have a home-based care kit

The data showed that 24 (34.3%) respondents indicated that they used plastic containers and 10 (14.3%) respondents indicated that they used their own bags to carry items needed in caring for patients at home. The remaining 36 (51.4%) respondents owned home-based care kits.

4.5 Personal experiences and coping strategies of home-based caregivers

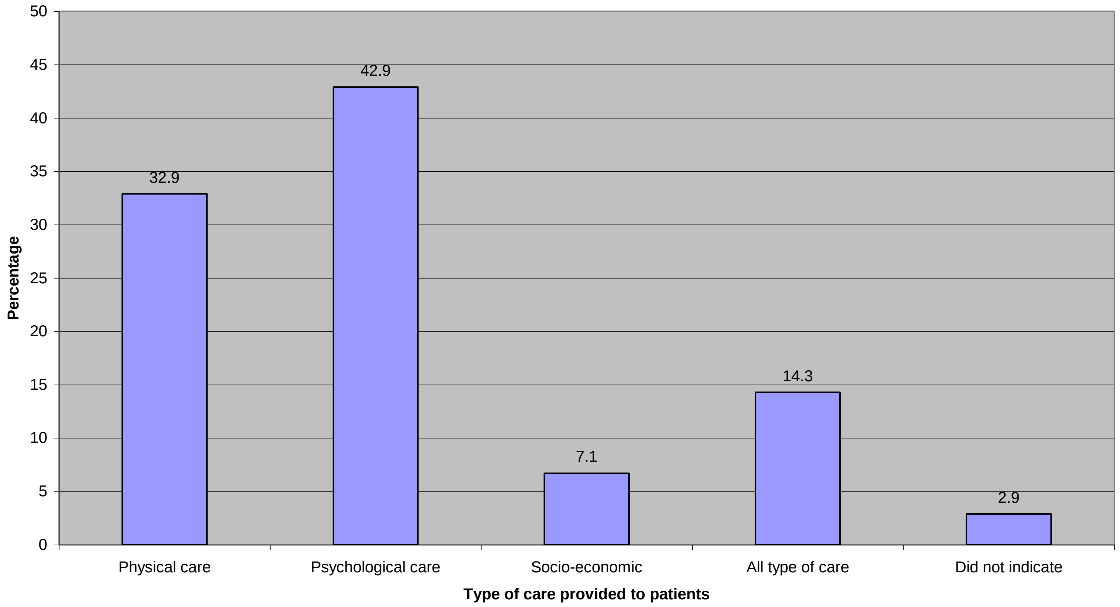
4.5.1 Acceptance of home-based caregivers by patients

Data show that 47 (67.1%) respondents were positively accepted as home-based caregivers while twenty-three (32.9%) respondents were not readily accepted as home-based caregivers.

4.5.2 Types of care provided to patients

The data showed that 23 (32.9%) respondents indicated that they provided only physical care to HIV/AIDS patients; 30 (42.9%) respondents provided spiritual or psychological care; five (7.1%) respondents indicated that they offered socio-economic support and care; and 10 (14.3%) respondents indicated that they offered physical, spiritual and socio-economic care to patients. Two (2.9%) respondents did not indicate anything.

Figure 4.7: Type of care for patients (N = 70)



4.5.3 **Caring for patients the whole day**

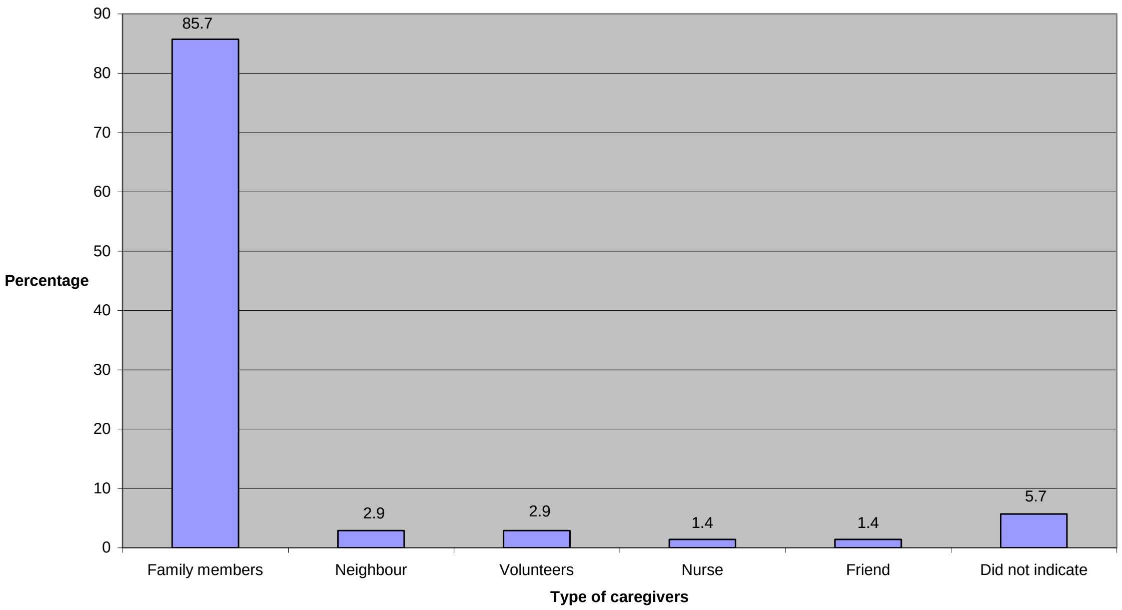
The data showed that 16 (22.9%) respondents indicated that they took care of their patients the whole day, while 52 (74.3%) respondents indicated that they did not attend to and take care of their patients the whole day. Two (2.9%) respondents did not respond.

4.5.4 **Others assisting home-based caregivers in caring for patients at home**

The data showed that 60 (85.7%) respondents indicated that they received assistance from family members in caring for patients at home; two (2.9%) respondents were assisted by their neighbours; two (2.9%) respondents were assisted by volunteers; one

(1.4%) respondent was received assistance from a friend; and one (1.4%) respondent was assisted by a nurse. Four (5.7%) respondents did not indicate anything.

Figure 4.8: Others assisting home-based care providers in caring for the patients at home (N = 70)



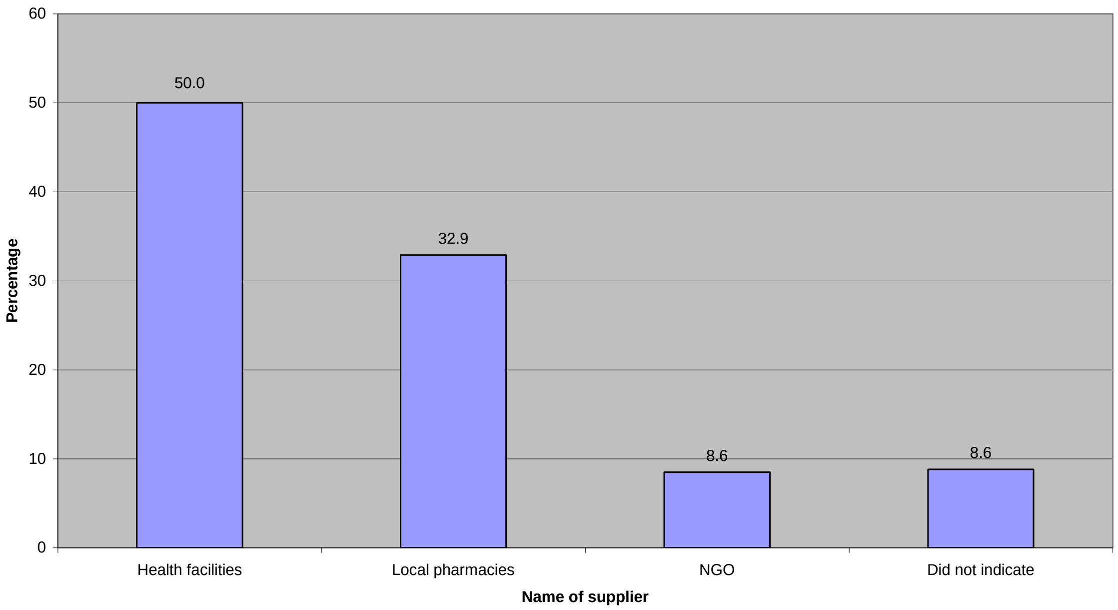
4.5.5. Effects of caring for patients on home-based caregivers

The data revealed that the largest number of 57 (81.4%) respondents experienced physical, psychological and social effects in their work. Thirteen (18.6%) respondents did not indicate anything.

4.5.6 Suppliers of protective gloves

The data showed that 35 (50.0%) respondents obtained gloves from health facilities; 23 (32.9%) obtained gloves from local pharmacies; and six (8.6%) respondents obtained gloves from NGOs. Six (8.6%) respondents did not indicate who supplied them with gloves.

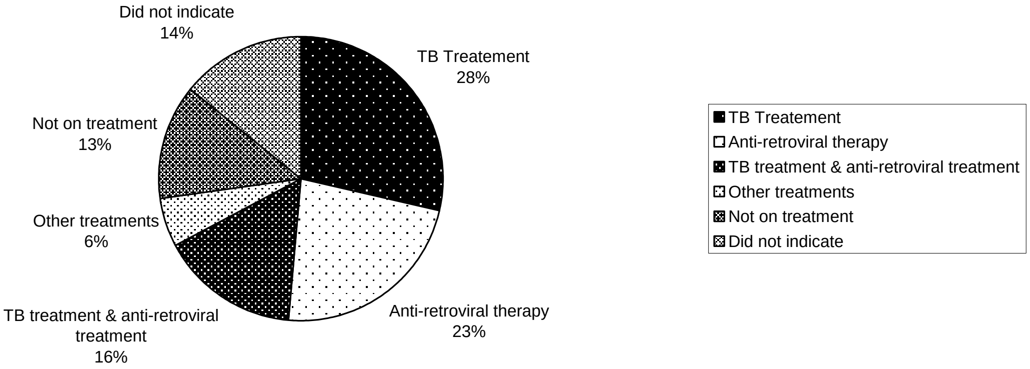
Figure 4.9: Supplier of protective gloves (N = 70)



4.5.7. **Caring for patients who are on medical treatment**

The data revealed that 20 (28.6%) respondents took care of patients who received TB treatment; 16 (22.9%) mentioned that their patients were receiving ART; 11 (15.7%) respondents indicated that they had some patients who were receiving TB treatment and some who were receiving ART; four (5.7%) respondents indicated that their patients received various medical treatment (such as bactrim prophylaxis, antidiarrheal medication, vitamin supplements and cough suppressants). Nine (12.9%) respondents indicated that their patients were not yet on any treatment. Ten respondents did not indicate anything.

Figure 4.10: Caring for patients on medical treatment



4.5.8 **Person responsible for administering medication to patients**

The largest number of respondents 46 (65.7%) indicated that administering medication was the responsibility of relatives; 18 (25.7%) respondents indicated that medication was administered by volunteers; four (5.7%) respondents indicated that patients were responsible for administering medication by themselves; and one (1.4%) respondent indicated that medication was administered by a friend. One (1.4%) respondent did not indicate anything.

Table 4.13: Person responsible for administering medication to patients

(N = 70)

Person responsible for giving medicine	**Frequency**	**Percentage**
Patients	4	5.7
Relatives	46	65.7
Volunteers	18	25.7
Friends	1	1.4
Did not indicate	1	1.4
Total	**70**	**100**

4.5.9 Compliance with treatment

The data showed that 19 (27.1) respondents indicated that their patients complied with their treatment regimes and 32 (45.7%) respondents mentioned that their patients refused to comply with their treatments. Nineteen (27.1%) respondents did not respond to this question.

4.5.10 Experiences of home-based caregivers caring for HIV/AIDS-infected patients

The data revealed that 62 (88.6%) respondents indicated that they experienced caring for HIV and AIDS patients as demanding, exhausting and challenging. Seven (10%) respondents indicated that they enjoyed caring for HIV and AIDS patients. One (1.4%) respondent did not indicate anything.

4.5.11 **Problems home-based caregivers face**

The data revealed that 62 (88.6%) respondents indicated that they faced problems in caring for HIV/AIDS-infected patients, while seven (10.0%) respondents mentioned that they had no problems in caring for the HIV/AIDS-infected patients. One (1.4%) respondent did not respond to this question.

4.5.12 **Types of problems home-based caregivers face**

The data showed that 50 (71.4%) respondents indicated that they were poor and had no source of income; 40 (57.1%) respondents indicated that their patients were suffering from starvation due to a lack of adequate food in their households; 39 (55.7%) respondents mentioned a lack of protective equipment and material (such as a home-based care kit, protective gloves, an apron, face masks), and a lack of medication; 39 (55.7%) respondents mentioned a lack of transport, travelling long distances and an increased work load; 38 (54.3%) respondents indicated that they had limited knowledge, education and information about caring for HIV/AIDS patients and also no counselling skills; and 35 (50.0%) respondents indicated that some patients were kept hidden by their household members. Twenty-nine (41.4%) respondents revealed the problem of patients being neglected, rejected and discriminated against by family members and community members once their HIV status are disclosed. Three (4.3%) respondents did not indicate their problems.

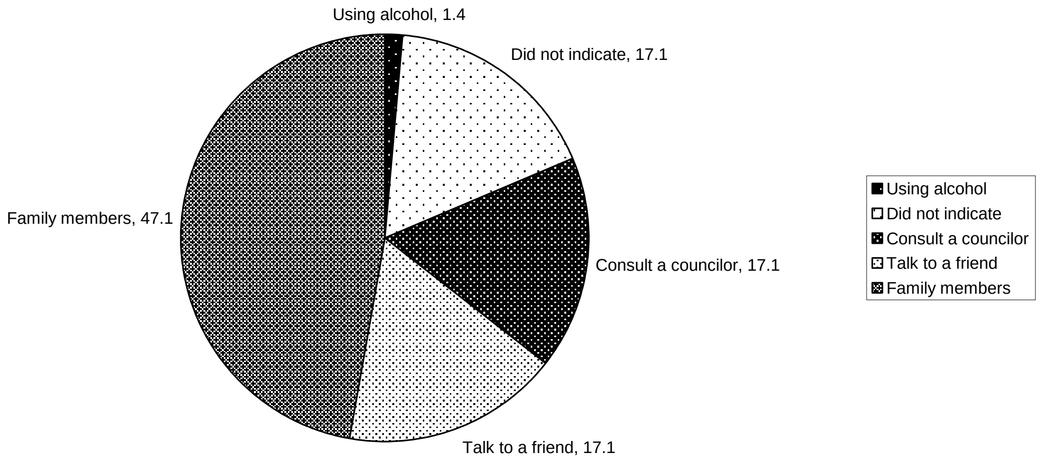
4.5.13 **Coping mechanisms**

The data showed that 53 (75.7%) respondents indicated that they coped with caring for patients at home, while 17 (24.3%) respondents revealed that they did not cope.

4.5.14 **Coping strategies home-based caregivers use**

The data revealed that 33 (47.1%) respondents talked to family member as a coping strategy; 12 (17.1%) respondents talked to a friend; 12 (17.1%) respondents consulted a counsellor; and one (1.4%) respondent used alcohol. Twelve (17.1%) respondents did not respond to this question.

Figure 4.11: Coping strategies used by home-based care providers



4.6 Types of support provided to HIV/AIDS-infected patients

4.6.1 Types of spiritual care rendered to critically ill patients by home-based caregivers

The data showed that 43 (61.4%) respondents indicated that they prayed, sang and read the Bible to provide spiritual care to their patients; 11 (15.7%) respondents indicated they asked a pastor for assistance; and nine (12.9%) respondents did spiritual counselling. Seven (10.0%) respondents were assisted by neighbours and friends.

4.6.2 People consulted to render spiritual care to terminally or critically ill patients facing the last stage of life

The data revealed that 63 (90.0%) respondents indicated that they consulted a pastor, and six (8.6%) respondents consulted a psychologist or any other spiritual counsellor. One (1.4%) respondent did not respond to this question.

4.6.3 Caring for patients who are facing the end of their lives

The data showed that 43 (61.4%) respondents indicated that they offered moral support to patients and 20 (28.6%) respondents indicated that they had never attended to a dying patient. Seven (10.0%) respondents did not answer this question.

4.6.4 Types of support systems available in the community

The data revealed that 10 (14.3%) respondents indicated that they received donations from the community; nine (12.9%) respondents were assisted with transport by the community; and 20 (28.6%) respondents received moral support and encouragement from their communities. Thirty-one (44.3%) respondents indicated that no assistance and support were available in their communities.

4.6.5 **How support systems assist home-based caregivers at community level in caring for HIV/AIDS-infected patients**

The data showed that 39 (55.7%) respondents indicated the following:

- Food donations helped non-professional caregivers to provide food to patients who had no food or limited food.
- Soap and vaseline (petroleum jellie) were used in providing for the personal hygiene needs of patients.
- Gloves and carry bags were used in caring for patients who had sores or diarrhoea, or when non-professional caregivers themselves had wounds on their hands or elsewhere on their bodies, in order to prevent infection and transmission of disease. Some of the non-professional caregivers revealed that they themselves were infected with HIV and they did not want to infect others.
- Moral support and encouragement helped professional caregivers to obtain new inspiration and courage in their daily activities. It helped them to recognise the worthiness of providing home-based care.
- Assistance with transport was twofold: transporting sick patients to the hospital and transporting home-based caregivers to health facilities, either for reporting on the

progress of patients and/or refilling the home-based care kit and collecting other requirements used during home-based care.

- Money provided help in various ways, especially in travelling and transporting patients to hospital. Money was also used to make telephone calls when the home-based caregivers needed to send reports of their patients to health facilities or to request gloves and other material required in caring for the patient at home.

Thirty one (44.3%) respondents did not respond to this item.

4.6.7 **Home-based caregivers' strategies for addressing their needs**

Some of the respondents recommended the following strategies for addressing their physical, moral, emotional and social needs when caring for HIV/AIDS patients at home:

- Establishment of support groups at community level to provide moral support.
- Establishment of a community centre in each constituency where, if possible, all the necessary equipment and material required for home-based care can be found.
- Provision of a home-based kit to all home-based caregivers.
- Provision of analgesics and dressing material.
- Increased training opportunity for home-based caregivers that might help to increase their knowledge and skills in home-based care.
- Increase the number of trained home-based caregivers to reduce the problem of travelling long distances and work overload.

- Educate the community, especially the patients and their affected family members, to appreciate the presence of home-based caregivers and accept their assistance.
- Develop strategies to reduce stigmatisation and discrimination against HIV/AIDS-infected patients.

- The government and NGOs should play a major role in providing the following:
    - adequate gloves, face masks, dressing material, napkins or linen savers, Savlon and Dettol (or any disinfectant of this kind)
    - food to all terminally ill patients, especially those who are on treatment for TB and ARV
    - incentives or allowances to all home-based caregivers for basic needs, transport, and correspondence or communication
    - a disability fund for all terminally ill HIV/AIDS patients for purchasing food, medication and home-based care kits

4.7 **Summary**

In this chapter the data was analysed and presented according to the major research findings. The chapter was constructed based on the following research findings: introduction, profile of home-based caregivers, home-based caregivers’ knowledge about HIV and AIDS, protective measures used by home-based caregivers, personal experiences and coping strategies of home-based caregivers, types of support provided to the home-based caregivers of HIV/AIDS-infected patients.

CHAPTER 5

CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

5.1 Introduction

This chapter focuses on the recommendations, conclusions and limitations of the study. The conclusions were made according to the major research findings and objectives.

5.2 Discussions of findings

Objective 1

To describe the profile of home-based caregivers of HIV/AIDS-infected patients in the Onandjokwe Health District (see the research questionnaire, section A: questions 1 – 9; section B: questions 10 – 18; and section C: questions 52 – 54).

The following conclusions were arrived at on this objective.

The data indicated that female caregivers were more involved in home-based care than male caregivers. This could be because mothers are the primary caregivers by nature. Even in ancient times, women cared for patients in their home environment. Moreover, Kavuma et al (2004:578) indicate that there are factors (such as cultural, social and economic factors) that influence male involvement in home-based care programmes.

According to the research findings, 27.1% of the respondents were young caregivers ranging between 15 and 31 years.

This has an influence on their education and opportunities for future employment. Their chances of schooling become narrower and limited due to their caring responsibilities. According to Phororo (2002:11), the burden of home-based care fall on the women in the family, with girls drawn out of school because education is no longer seen as a priority.

The data showed that 40 (57.1%) of the respondents had received a secondary school education. The level of education of non-professional caregivers plays a major role in caring for HIV/AIDS patients. It determines the feasibility of the training capacity of individual home-based caregivers. It should be noted that in order to obtain knowledge and skills, home-based caregivers should have extensive or advanced training in home-based care. A broader knowledge on home-based care was essential to meet the needs of HIV/AIDS-infected patients.

The research findings revealed that 97.1% respondents had religious affiliations. Knowing the religious denominations to which respondents belong helps in understanding the influence of religion on caring for HIV and AIDS patients.

The type of accommodation influences the care of the patient at home. Home-based care should be provided in an environment that is suited to patients for whom their own homes are the most supportive and therapeutic settings for care. Besides this, home-based care and established home visiting services should go hand in hand with comprehensive health education to ensure that patients are cared for on a continuum. However, according to the findings of the research, the opposite is true due to limited human and other resources.

It was concluded that most caregivers live in traditional homes, which could influence the health of the patients in terms of clean water supply, latrines and living standards. The data revealed that 38.6% respondents used the radio as a means of communication; 27.1% of home-based caregivers were unemployed, which probably means that they had no regular source of income; and only 7.1% of the respondents were formally employed.

The employment status of home-based caregivers had an influence on their income because they were under pressure to combine caring for HIV/AIDS-infected patients with formal employment. The pressure became great as soon as the HIV/AIDS-infected patient became bedridden, whereby the caregiver had to apply for leave or absence from work. Ten percent of home-based caregivers were self-employed. This also had implications for the level of caring. On the positive side, self-employment brought in money needed for food, medication, soap and transport fees. On the negative side, there may be no-one else to care for the patient and to assist with feeding, bathing and administering medication, especially if nobody is helping core caregivers.

Furthermore, it was concluded that home-based caregivers lived with other household members: 34.3% of respondents indicated that they had six to 10 people in the same household and 35.7% stayed with 11 to 15 people. The presence of other people in the household influenced the caring role of caregivers. The influence is determined by gender roles, since female caregivers have multiple roles that are culturally determined as having to be fulfilled by women only.

The research findings revealed that most (51.4%) of the home-based caregivers had one to three children under the age of five years in their households. The age of the children influenced the caring ability of the caregivers, because children under five need close supervision.

The data indicated that employed people were paid below the poverty level. This was revealed by 31.4% respondents who indicated that their family members who earned a salary received less than N$500.00 per month; 22.9% respondents received a monthly salary between N$501.00 and N$1999.00. This data indicated that the salaries were inadequate to meet household expenditure. Twenty percent of the respondents indicated that none of their household members earned a monthly salary. This meant these caregivers lived in absolute poverty.

Most (52.9%) of the respondents obtained an income from farm products. It can be assumed that the sheer burden of providing care did not allow caregivers opportunities to participate in income generating activities that are important for their survival and livelihood.

The research findings revealed that 71.4% of the home-based caregivers used to walk frequently to reach the households of HIV/AIDS-infected patients. Therefore, it can be concluded that there was a lack of transport. The data further indicated that non-professional caregivers had to travel more than 5km in order to reach health facilities. This indicated that health facilities are not within reach of communities in rural areas. Home-based caregivers travelled long distances to look for medical help for their patients.

This problem of lack of transport is not only confined to the Onandjokwe Health District; it is also prevalent in other countries. According to Chola (2003:21), in Zambia caregivers (especially relatives) used to bring their chronically ill patients to the clinic by transporting them in wheelbarrows, on bicycles or on the backs of people. This indicates that caregivers try their best to use whatever is available and affordable.

The research findings revealed that the training of home-based caregivers was not standardised because they were trained for different periods of time. This did not enable home-based caregivers to possess all the knowledge and skills required to meet the needs of infected patients and their affected family members. It might be that limited training leads to a knowledge deficit. Follow-up training were lacking and most of the time such services were non-existent at home level. The situation was worse in rural areas. The research findings further revealed that various NGOs were involved in training home-based caregivers.

The data on the training agencies included the following: Katonyala Home-based Care trained 37.1% of the respondents, ELCIN trained 30.0%; and other were trained by Lifeline/Childline, Lironga Eparu and other individuals. This indicated that training in home-based care existed at community level.

Objective 2

To determine the knowledge of home-based caregivers about HIV and AIDS patients in the Onandjokwe Health District (see the research questionnaire, section B: questions 19 – 24).

Despite the fact that home-based caregivers received training, it was concluded that respondents lacked knowledge concerning HIV/AIDS on the following aspects.

HIV/AIDS concepts, mode of spread, and symptoms and signs: In general, the findings were in line with the findings of authors such as Young et al (2003), Mahatelo (2003) and Jariyavilas et al (2003:14) who state that most home-based caregivers have limited knowledge on HIV and AIDS. HIV and AIDS do not discriminate and therefore it flourishes and spreads in all possible ways.

Objective 3

To explain the protective measures home-based caregivers of HIV and AIDS patients in the Onandjokwe Health District use (see the research questionnaire, section B: questions 30 – 40).

Based on the research findings, it was concluded that 92.9% home-based caregivers used protective measures. Only 5.7% respondents did not use protective measures. It was revealed further that the reason for using protective measure was to prevent contamination, cross infection and co-infection between caregivers and infected patients. This was indicated by 50.0% of caregivers who used plastic containers to protect their hands when caring for HIV and AIDS patients. This indicated that home-based caregivers used whatever is available if no protective gloves are available.

It was concluded that home-based caregivers handled and discarded soiled materials in a proper way. They burned or buried material that could not be reused, and soaked soiled linen in disinfectants such as Dettol or Savlon.

It was concluded that 51.4% of the home-based caregivers had home-based care kits. The home-based kit contains items that are needed for home-based care.

Objective 4

To explore the personal experiences of home-based caregivers in the Onandjokwe Health District (see the research questionnaire, section B: questions 26 – 29, 35, 41 – 48).

The research findings revealed that 67.1% of caregivers were positively accepted as home-based caregivers, while 32.9% respondents were not readily accepted as caregivers. Non-acceptance as caregivers might be due to the prevalence of stigmatisation and discrimination attached to the HIV/AIDS disease in the community. According to Chola (2003:22), acceptance can be obstructed when stigmatisation of HIV is strong in communities. Sometimes lack of acceptance is caused by a lack of counselling and awareness about HIV infection. It may also be due to "secondary stigmatisation". Visiting home-based caregivers may cause fear that a visit to the household of HIV/AIDS-infected patients will reveal their HIV status to family members and neighbours.

The findings of the study are in line with what (Mahatelo 2003:8) found: everyone is unnerved by the silence surrounding HIV and AIDS. There is also the problem of secondary stigmatisation: members of home-based care teams sometimes find themselves shunned by people who fear that their painful secret will be revealed to the neighbours. Even wearing gloves, especially in the home, has become a sensitive issue because of its association with HIV.

The findings indicated that family members do assist home-based caregivers in caring for patients. However, home-based caregivers experienced physical, psychological and social effects during their caring activities. They indicated that they feel that home-based care is challenging, demanding and exhausting.

The data showed that 65.8% respondents mentioned that relatives of patients who are on treatment have taken the responsibility of administering medication to their patients. This means that relatives and family members are responsible for performing the role of caregiver at home.

The research findings showed that only 27.1% respondents' patients were able to comply with treatment; 45.7% respondents indicated lack of compliance due to side-effects and lack of food. This indicates that for in order for compliance to occur, patients need adequate food, a treatment supporter and knowledge concerning the adverse effects of not complying with treatment.

The findings of the study also revealed the following:

The problem of poverty was related to lack of income by 71.4% of the respondents; 57.1% respondents indicated that their patients suffered from starvation due to lack of adequate food in households; 55.7% respondents indicated a lack of protective equipment, lack of transport and difficulty in travelling long distances; 54.3% respondents indicated that they had limited knowledge, education and training skills;

50.0% respondents indicated that patients are hidden by household members; and 41.4% respondents revealed that patients felt neglected and discriminated against.

Of the respondents 75.7% indicated that they coped in caring for patients through the assistance of family members; 47.1% respondents consulted or talked to family members; 17.1% respondents talked to a friend; and 17.1% respondents consulted a counsellor. Only one 1.4% respondent indicated using alcohol as a coping strategy.

Objective 5

To identify the types of support home-based caregivers provide to HIV/AIDS-infected patients (see the research questionnaire, section B: questions 49 – 51; section C: questions 55 – 56; and section D: question 57).

It was concluded that respondents provided physical, spiritual and psychological care and financial support to patients. However, due to a lack of knowledge on counselling skills this is not always done properly. Counselling and psychological support is especially important when stigmatisation and secondary stigmatisation occur.

5.3 **Recommendations**

- Provide home-based care kits to all home-based caregivers.
- Design training curricula with a wide range of knowledge and skills that non-professional caregivers require in order to provide a high standard of holistic care and support.
- Develop standarised training.
- Liaise with other training providers. This requires a written arrangement in order to make it accessible for use by other organisations that will contribute to the training of non-professional caregivers. It could include community-based organisations (such as ELCIN, CAA and Lifeline/Childline) providing training in HIV/AIDS, child care and TB.
- Develop strategies that encourage and support increased male involvement in community home-based care initiatives.
- Establish strategies that enhance good health, and strengthen self-care and coping skills.
- Establish strategies that are required to reduce vulnerability related to personal and socio-cultural factors (such as poverty reduction; access to health services; acceptance of condom use; confronting issues of silence, secrecy and stigmatisation; and addressing women's rights.
- Train non-professional caregivers by addressing practical issues regarding home-based care, including general hygiene, nutrition and universal precaution.

- Develop appropriate strategies to reduce discrimination and adopt a human rights approach to the pandemic.
- Provide adequate gloves, disinfectants, bleach, dressing material and medication.
- Develop and maintain an appropriate and sustainable home care kit.
- Provide ARV drugs to patients who are infected with the virus, irrespectively of their CD 4 count. This should also include infected non-professional caregivers. There is a need for palliative care to promote patient’s comfort and alleviate pain.
- Develop policies and guidelines of a new framework that promotes rights, dignity, equal access to care and non-discriminatory practices.
- Promote access to services for the greatest number of patients.
- Provide comprehensive services that address the full range of identified needs, such as the right to privacy and confidentiality.
- Promote a fair and equal distribution of services.
- Empower patients and their caregivers to make decisions on the use of the existing continuum of care services that effectively and efficiently link recipients between hospitals and their homes.
- Maximise patient responsibilities for long-term care (ie self-help, self-care and mutual advocacy).
- Provide information to patients, their families and all relevant social contacts.
- Develop and maintain a support system for PLWHA and their caregivers in order to alleviate stress and increase the capacity to cope. This could help patients and their families to develop positive coping skills.

- Develop strategies to openly discuss stigmatisation and mechanisms for sharing collective experiences in an attempt to understand stigmatisation and implementing measures to alleviate it as an obstacle to HIV prevention, diagnosis, care and support.
- Integrate community-based home care into the national health care system. This will link people to the national health care system and will help non-professional caregivers in dealing with the problems they face in caring for HIV/AIDS patients by following a multi-sectoral approach.
- Conduct training, workshops and seminars to keep abreast of information, and to create room for sharing information and problems that affect the daily activities of non-professional caregivers.
- Establish food schemes for all patients, the disabled and vulnerable children. Distribute resources evenly among all HIV/AIDS sufferers (eg provisions of a disability fund should be given to all HIV/AIDS-infected patients throughout the country).
- Find resources to support non-professional caregivers. This support can include provision of incentives and allowances to non-professional caregivers trained in home-based care (eg a paid minimum salary or at least providing money for transport). Funds are needed to finance home-based care programmes.
- Supervise home-based care activities, especially in the case of critically ill patients who need special treatment and care, and also psychosocial support and acceptance.

- Caring for caregivers. Attention/support should be given to those who are responsible for caring for non-professional caregivers. This is vital in providing moral support to non-professional caregivers. It is therefore vital to incorporate care for non-professional caregivers into the home-based care programme. Competent and skilled professionals are needed who have experience in providing psychosocial support.
- Establish and develop policies and guidelines for the proper functioning of home-based care in order to prevent problems as far as possible. This should include job descriptions for non-professional caregivers, conditions of services, a financial policy, a confidentiality and disclosure policy, a care policy (eg guidelines for dealing with specific symptoms) and a referral policy for referrals between service components.
- Develop strategies that connect home-based care with the social welfare services required to deal with financial assistance.
- Develop strategies that will help volunteers to work in improved conditions, and will protect them against harassment and embarrassment.
- Current community home-based care practices with regard to the quality of patient care and quality of life of patients and their families should be reviewed urgently.
- Develop and discharge planning and proper referral systems to involve all caregivers at home and to prevent hospitals from becoming congested and overcrowded health facilities.
- Increase political commitment through raising awareness and social mobilisation.

- Look for donor organisations to fund home-based care. We know that community ownership goes along with in sustaining a programme. As was stated previously: there is no such thing as a sustainable free service, even if everybody involved starts off as volunteers. This is only possible by asking assistance from donors in order to guarantee the sustainability of home-based care and assistance from government, especially in these difficult times when most households are affected by HIV/AIDS.
- Develop well-established referral systems.
- Recognise PLWHA as caregivers by addressing their specific needs for the provision of care, thus facilitating their capacity to play key roles in HIV/AIDS prevention, care and education.
- Establish centres with one-stop counselling rooms that contain all the requirements for home-based care so that non-professional caregivers can counsel their patients. These centres should be established and built close to health facilities so that it makes it possible for non-professional caregivers and health teams to share ideas on caring for HIV/AIDS patients.

5.4 **Recommendations for further study**

Due to the limitation of this study (see section 5.4), the researcher feels that there is a need for investigating the following further:

- Strategies that can be utilised for proper integration of home-based care in the health care system at national level. The researcher would, therefore, like to recommend further research on the establishment of a policy related to home-based care programmes.

- The extent to which home-based care potentially puts the non-professional caregiver at risk of being infected by HIV/AIDS.

5.5 Limitations of the study

The study was limited to the population of the trained home-based care provider in the Oshikoto Region because of the following reasons and constraints.

The diversity of the Namibian population is such that any scientific study of this kind has to be replicated and qualified with further research in other regions of Namibia. The ideas, opinions and views on the challenges facing trained home-based caregivers indicated by the respondents in the Onandjokwe Health District may not be the same as the ideas, opinions and views of home-based caregivers who care for HIV/AIDS patients in other regions. Thus the findings cannot be generalised.

5.6 Concluding remarks of the study

Because of the increased prevalence of HIV/AIDS in the Onandjokwe Health District, this study was done to serve as a guide on the impact of HIV/AIDS on the community. Previous research investigated the impact of HIV/AIDS on the nursing and medical profession without looking at non-professional caregivers. Much research was done that was mainly concerned with the health profession -- not with non-professional caregivers.

However, it should be remembered that HIV/AIDS affects also non-professional caregivers who care for patients at home.

This study found that some of the non-professional caregivers travelled long distances to care for patients. They included volunteers, neighbours, friends and some parents who did not live in the same house as the patients. Non-professional caregivers often attend to patients and are involved in other activities, especially those who participate in income generating activities and other social community events. This finding agrees with the literature. Nthabiseng (2001:2) states that providing care varies according to the amount of time and effort a caring individual can give, and according to the needs of those who require care. According to this source, in most cases family caregivers care for more than one patient. The results of this study indicated that home-based care is carried out under conditions of poverty.

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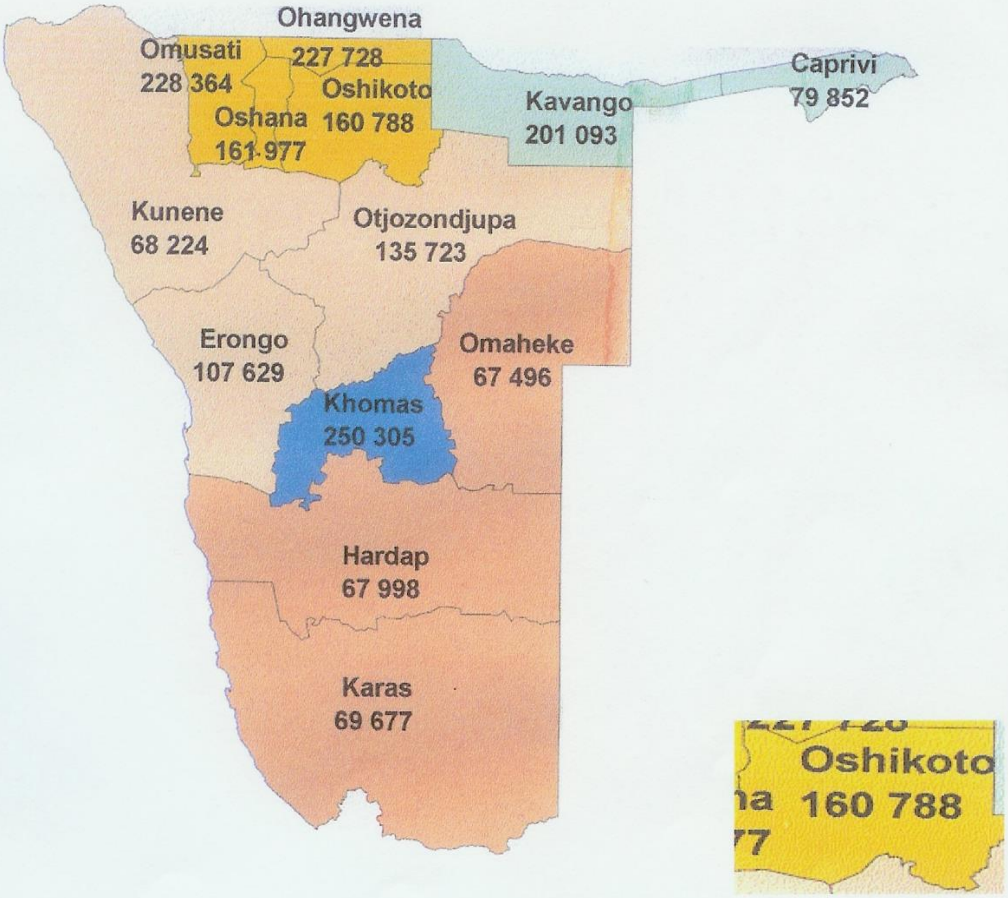
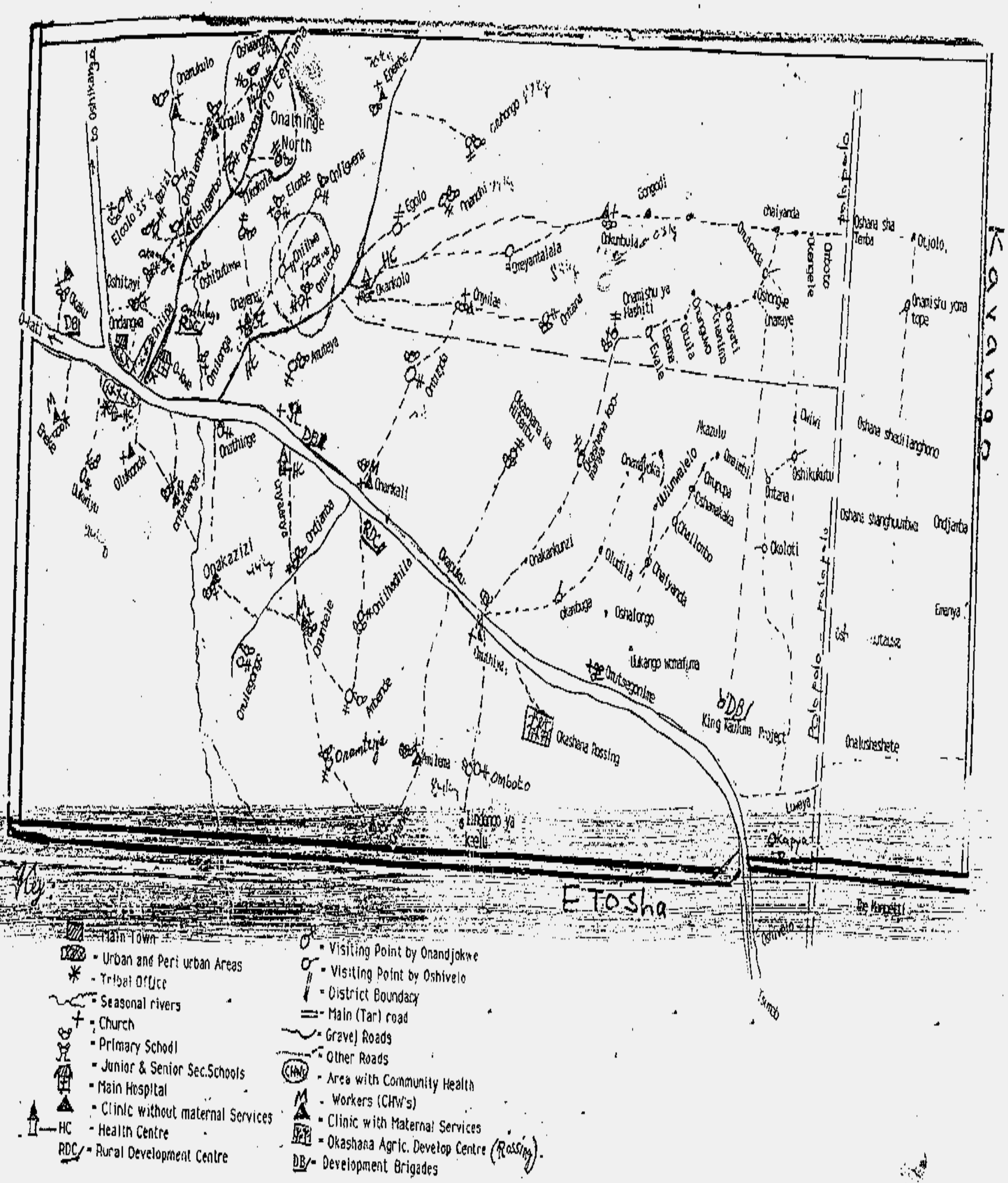
ANNEXURE A

MAP OF NAMIBIA AND ONANDJOKWE HEALTH DISTRICT, OSHIKOTO REGION

Map 1.1: Map of Namibia showing the areas/regions



AREA MAP OF ONANDJOKWE HEALTH DISTRICT - Total population 194 255 (1991 pop. cencus)



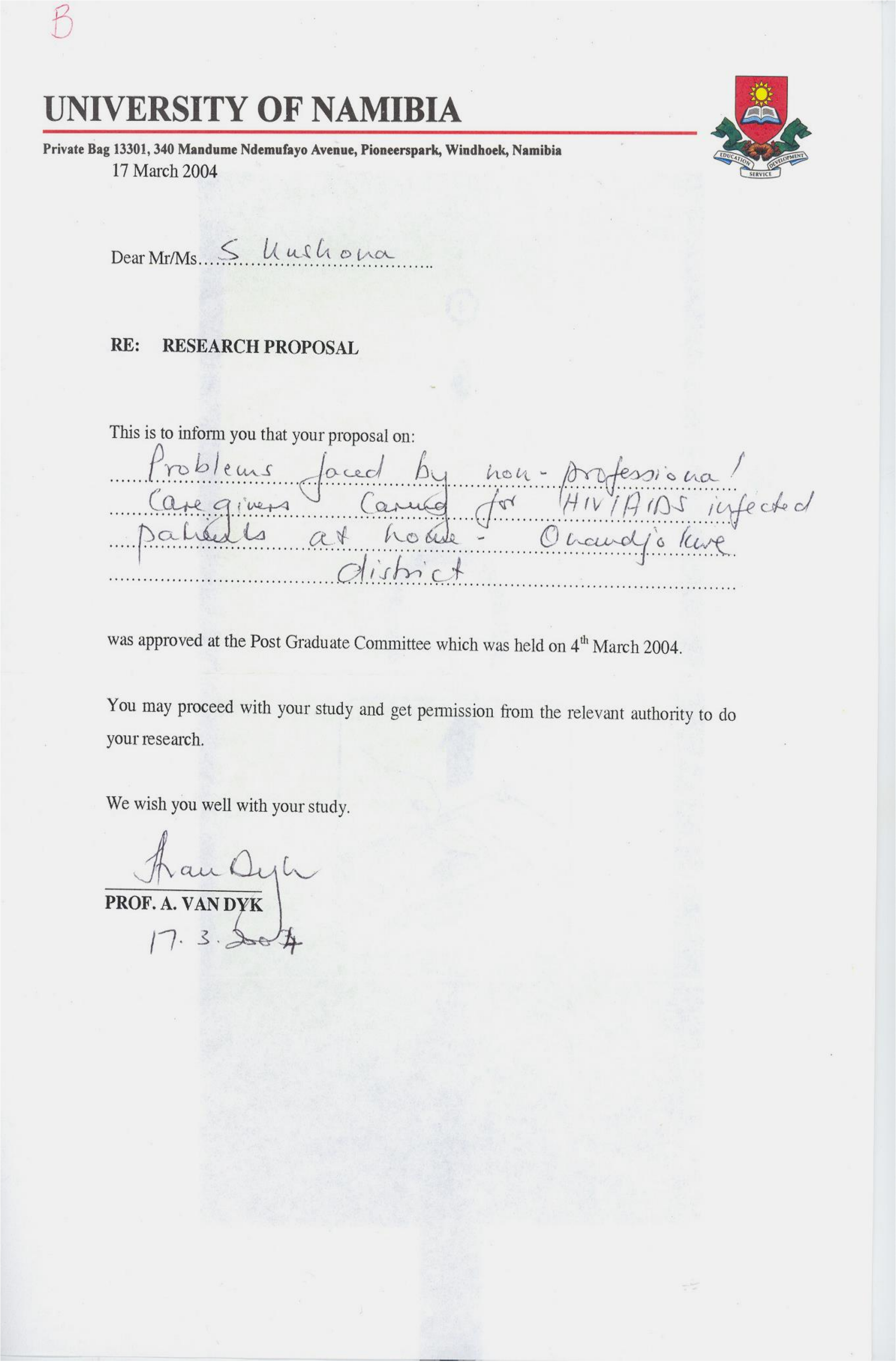
December, 1992

ANNEXURE B

APPROVAL LETTER

OF

RESEARCH PROPOSAL



B

UNIVERSITY OF NAMIBIA

Private Bag 13301, 340 Mandume Ndemufayo Avenue, Pioneerspark, Windhoek, Namibia

17 March 2004

Dear Mr/Ms S Uushona

RE: RESEARCH PROPOSAL

This is to inform you that your proposal on:

Problems faced by non-professional Care givers Caring for HIV/AIDS infected patients at home - Ouandjokwe district

was approved at the Post Graduate Committee which was held on 4th March 2004.

You may proceed with your study and get permission from the relevant authority to do your research.

We wish you well with your study.

A van Dyk

PROF. A. VAN DYK

17. 3. 2004

ANNEXURE C

APPLICATION LETTERS
TO CONDUCT RESEARCH
IN ONANDJOKWE HEALTH DISTRICT

Oniipa-Iyale
P.O. Box 901
Ondangwa
12 May 2004

The Permanent secretary
Ministry of Health and Social Services
Harvey street
Private bage 13198
Windhoek

Dear Sir

RE: APPLICATION FOR PERMISSION TO CONDUCT A RESEARCH IN ONANDJOKWE HEALTH DISTRIC – OSHIKOTO REGION

I am a full-time master's degree student at the University of Namibia, doing Public Health. As the requirement of my study, I would like to be given the permission to conduct the research project in Onandjokwe Health District.

The study title is: A descriptive study of home-based care provided to HIV and AIDS infected patients in Onandjokwe Health District Namibia.

The specific objectives of the study are to:

- describe the profile of home-based care providers of HIV and AIDS infected patient in Onandjokwe Health District.
- describe the knowledge of home-based care providers of HIV and AIDS patients in Onandjokwe Health District about HIV and AIDS.
- describe protective measures used by home-based care providers of HIV and AIDS patients in Onandjokwe Health District
- describe personal experience of home-based care providers of HIV and AIDS infected patients in Onandjokwe Heatlh District
- describe the type of support provided to HIV and AIDS infected patients by home-based care providers.

I humbly request your office to grant me permission to conduct this research project.

Thanking you in advance.

Yours faithfully

SUushona

Selma Ingandipewa Uushona

Oniipa-Iyale
P.O. Box 901
Ondangwa
12 May 2004

The District Supervisor
Onandjokwe PHC
Private Bag 2016
Ondangwa

Dear Madam

RE: APPLICATION FOR PERMISSION TO CONDUCT A RESEARCH IN ONANDJOKWE HEALTH DISTRIC – OSHIKOTO REGION

I am a full-time master's degree student at the University of Namibia, doing Public Health. As the requirement of my study, I would like to be given the permission to conduct the research project in Onandjokwe Health District.

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- describe personal experience of home-based care providers of HIV and AIDS infected patients in Onandjokwe Heatlh District
- describe the type of support provided to HIV and AIDS infected patients by home-based care providers.

I humbly request your office to grant me permission to conduct this research project.

Thanking you in advance.

Yours faithfully

S Uushona

Selma Ingandipewa Uushona

Oniipa-Iyale
P.O. Box 901
Ondangwa
12 May 2004

The Governor
Oshikoto Regional Council
P.O.Box 1116
Tsumeb

Dear Sir

RE: APPLICATION FOR PERMISSION TO CONDUCT A RESEARCH IN ONANDJOKWE HEALTH DISTRIC – OSHIKOTO REGION

I am a full-time master's degree student at the University of Namibia, doing Public Health. As the requirement of my study, I would like to be given the permission to conduct the research project in Onandjokwe Health District.

The study title is: A descriptive study of home-based care provided to HIV and AIDS infected patients in Onandjokwe Health District Namibia.

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- describe personal experience of home-based care providers of HIV and AIDS infected patients in Onandjokwe Heatlh District
- describe the type of support provided to HIV and AIDS infected patients by home-based care providers.

I humbly request your office to grant me permission to conduct this research project.

Thanking you in advance.

Yours faithfully

SIUushona

Selma Ingandipewa Uushona

Oniipa-Iyale
P.O. Box 901
Ondangwa
12 May 2004

The Regional Councilor
Oniipa Constituency
Ondangwa

Dear Sir

RE: APPLICATION FOR PERMISSION TO CONDUCT A RESEARCH IN ONANDJOKWE HEALTH DISTRIC – OSHIKOTO REGION

I am a full-time master's degree student at the University of Namibia, doing Public Health. As the requirement of my study, I would like to be given the permission to conduct the research project in Onandjokwe Health District.

The study title is: A descriptive study of home-based care provided to HIV and AIDS infected patients in Onandjokwe Health District Namibia.

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- describe personal experience of home-based care providers of HIV and AIDS infected patients in Onandjokwe Heatlh District
- describe the type of support provided to HIV and AIDS infected patients by home-based care providers.

I humbly request your office to grant me permission to conduct this research project.

Thanking you in advance.

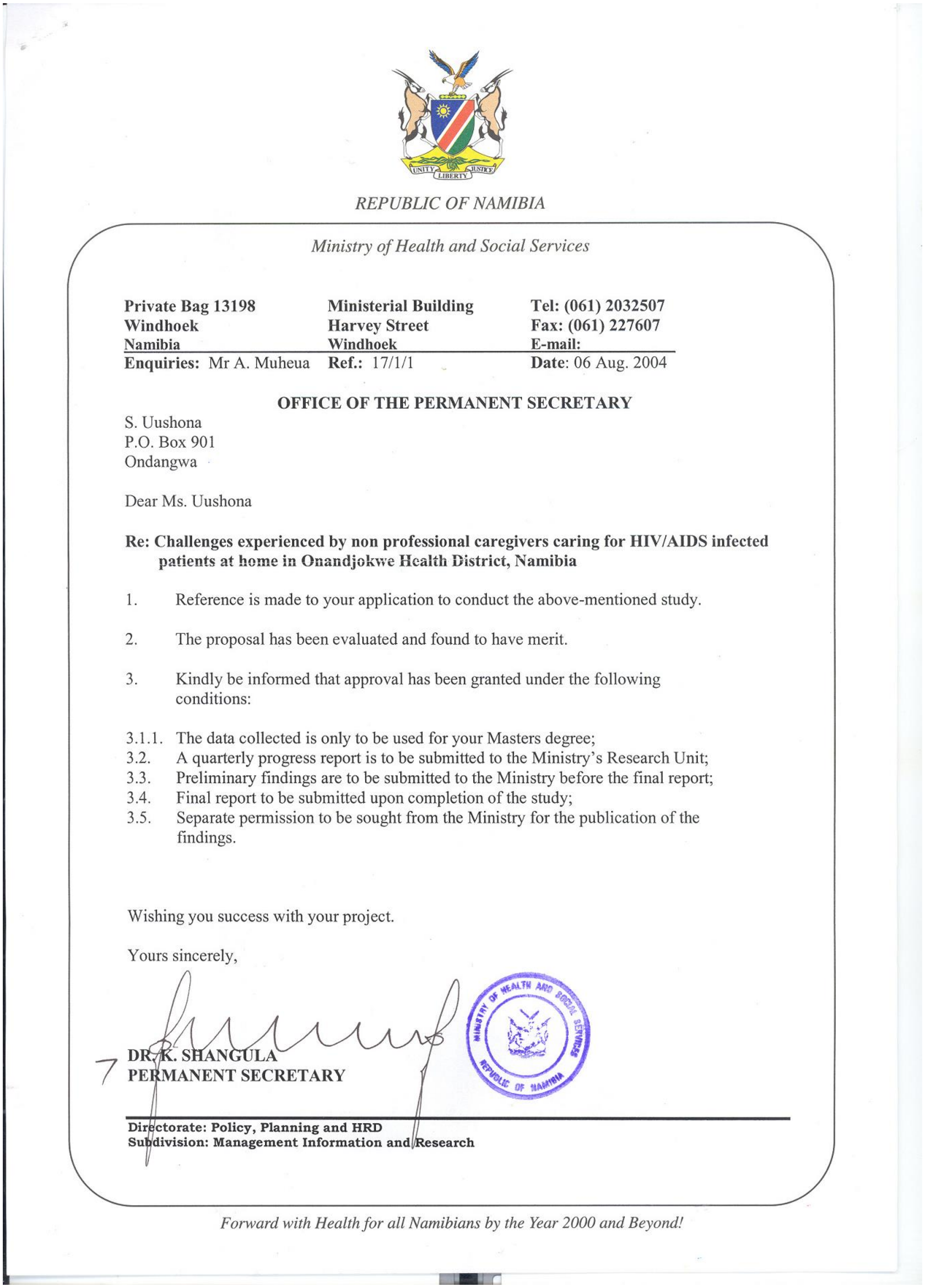
Yours faithfully

SIUushona

Selma Ingandipewa Uushona

ANNEXURE D

LETTER OF PERMISSION TO CONDUCT RESEARCH FROM THE MINISTRY OF HEALTH AND SOCIAL SERVICES



REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13198
Windhoek
Namibia

Ministerial Building
Harvey Street
Windhoek

Tel: (061) 2032507
Fax: (061) 227607
E-mail:

Enquiries: Mr A. Muheua **Ref.:** 17/1/1 **Date**: 06 Aug. 2004

OFFICE OF THE PERMANENT SECRETARY

S. Uushona
P.O. Box 901
Ondangwa

Dear Ms. Uushona

Re: Challenges experienced by non professional caregivers caring for HIV/AIDS infected patients at home in Onandjokwe Health District, Namibia

1. Reference is made to your application to conduct the above-mentioned study.

2. The proposal has been evaluated and found to have merit.

3. Kindly be informed that approval has been granted under the following conditions:

3.1.1. The data collected is only to be used for your Masters degree;
3.2. A quarterly progress report is to be submitted to the Ministry's Research Unit;
3.3. Preliminary findings are to be submitted to the Ministry before the final report;
3.4. Final report to be submitted upon completion of the study;
3.5. Separate permission to be sought from the Ministry for the publication of the findings.

Wishing you success with your project.

Yours sincerely,

DR. K. SHANGULA
PERMANENT SECRETARY

Directorate: Policy, Planning and HRD
Subdivision: Management Information and Research

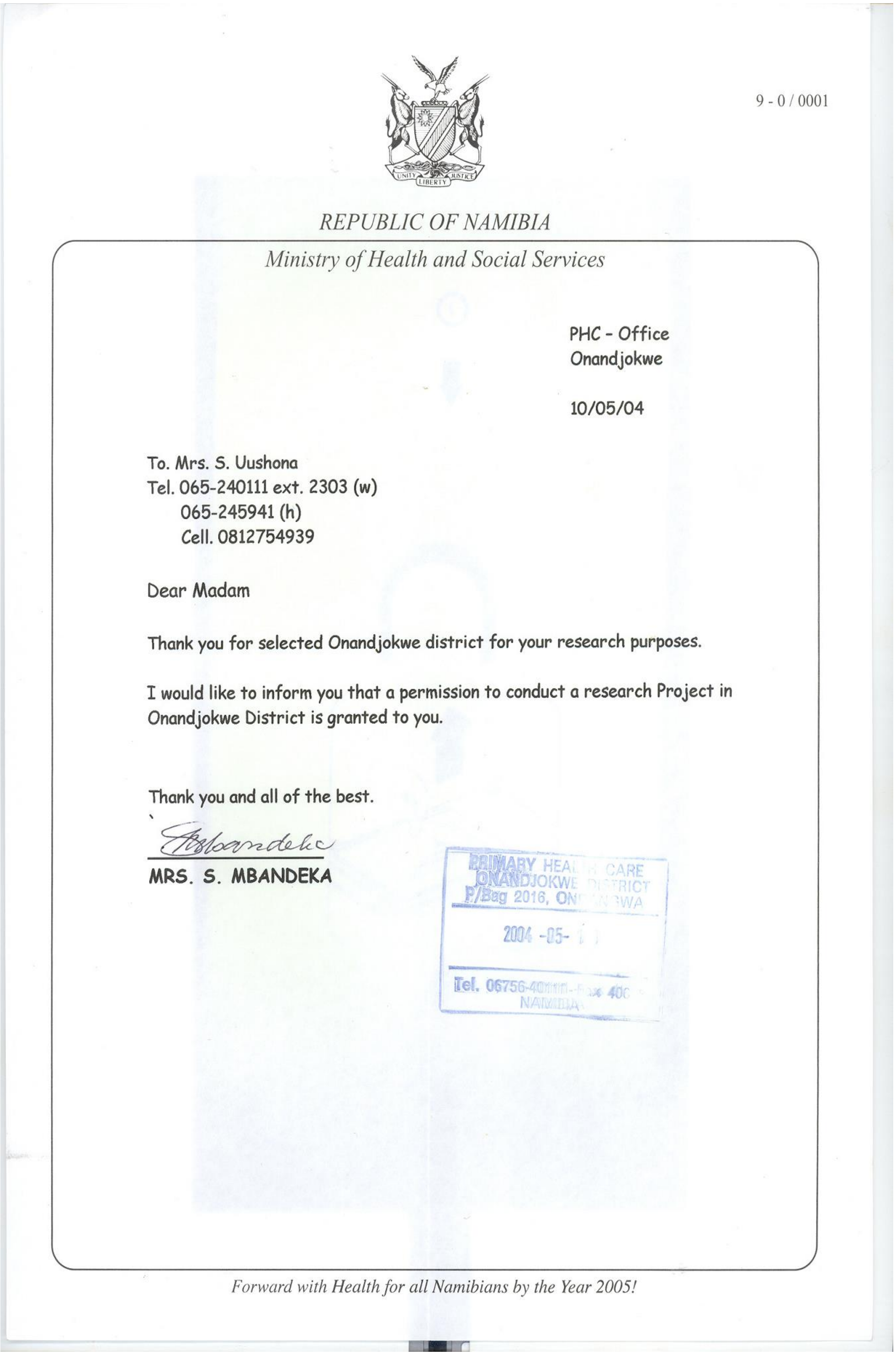
Forward with Health for all Namibians by the Year 2000 and Beyond!

ANNEXURE E

LETTER OF PERMISSION

TO CONDUCT RESEARCH

FROM ONANDJOKWE PHC SUPERVISOR



9 - 0 / 0001

REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

PHC – Office
Onandjokwe

10/05/04

To. Mrs. S. Uushona
Tel. 065-240111 ext. 2303 (w)
065-245941 (h)
Cell. 0812754939

Dear Madam

Thank you for selected Onandjokwe district for your research purposes.

I would like to inform you that a permission to conduct a research Project in Onandjokwe District is granted to you.

Thank you and all of the best.

MRS. S. MBANDEKA

PRIMARY HEALTH CARE
ONANDJOKWE DISTRICT
P/Bag 2016, ONDANGWA
2004 -05- [illegible]
Tel. 06756-40111 - Fax 400
NAMIBIA

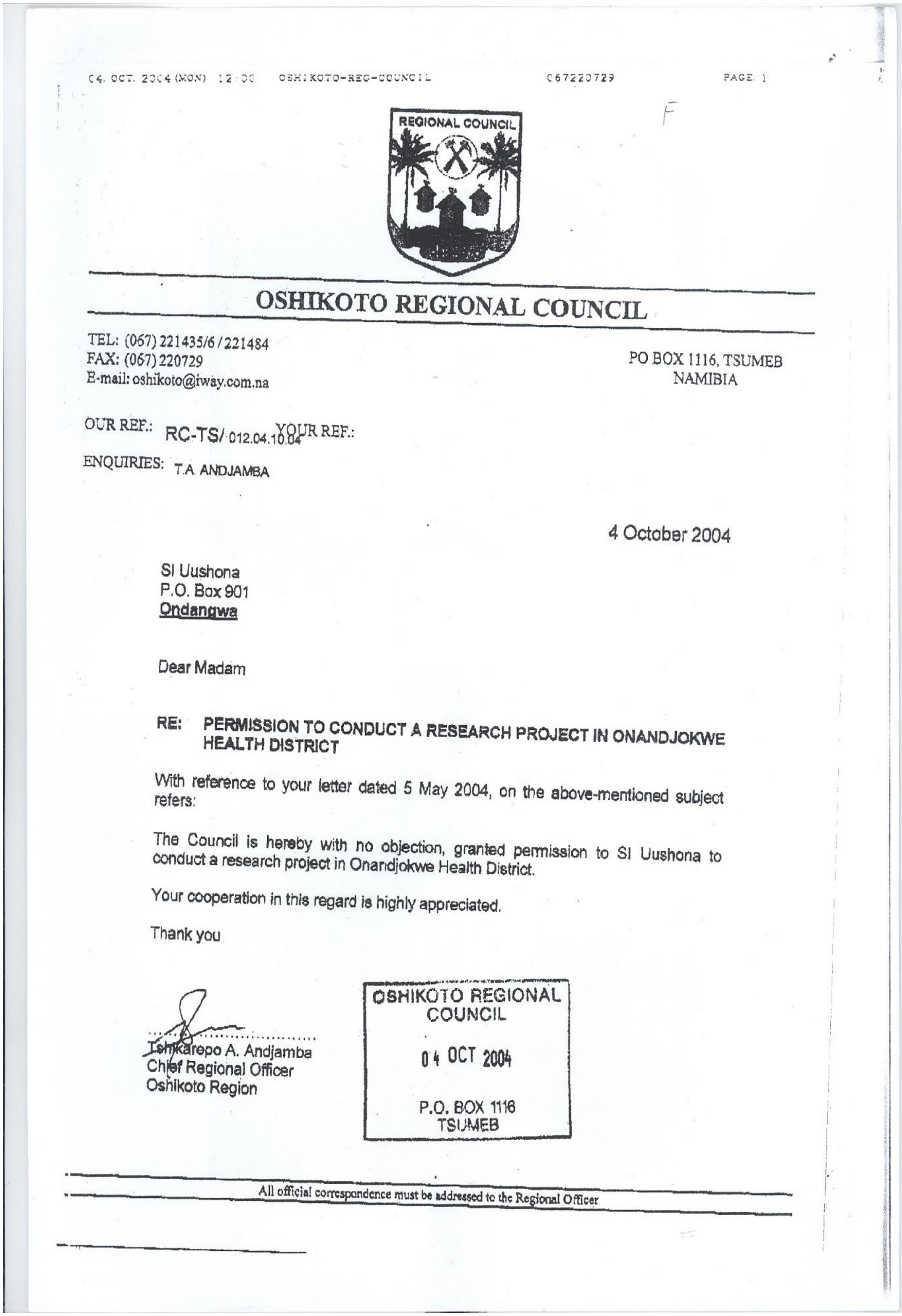
Forward with Health for all Namibians by the Year 2005!

ANNEXURE F

LETTER OF PERMISSION

TO CONDUCT RESEARCH

FROM OSHIKOTO REGIONAL COUNCIL



04. OCT. 2004 (MON) 12:00 OSHIKOTO-REG-COUNCIL 067220729 PAGE. 1

F

OSHIKOTO REGIONAL COUNCIL

TEL: (067) 221435/6 / 221484
FAX: (067) 220729
E-mail: oshikoto@iway.com.na

PO BOX 1116, TSUMEB
NAMIBIA

OUR REF.: RC-TS/012.04.10.04 YOUR REF.:

ENQUIRIES: T.A ANDJAMBA

4 October 2004

SI Uushona
P.O. Box 901
<u>Ondangwa</u>

Dear Madam

RE: PERMISSION TO CONDUCT A RESEARCH PROJECT IN ONANDJOKWE HEALTH DISTRICT

With reference to your letter dated 5 May 2004, on the above-mentioned subject refers:

The Council is hereby with no objection, granted permission to SI Uushona to conduct a research project in Onandjokwe Health District.

Your cooperation in this regard is highly appreciated.

Thank you

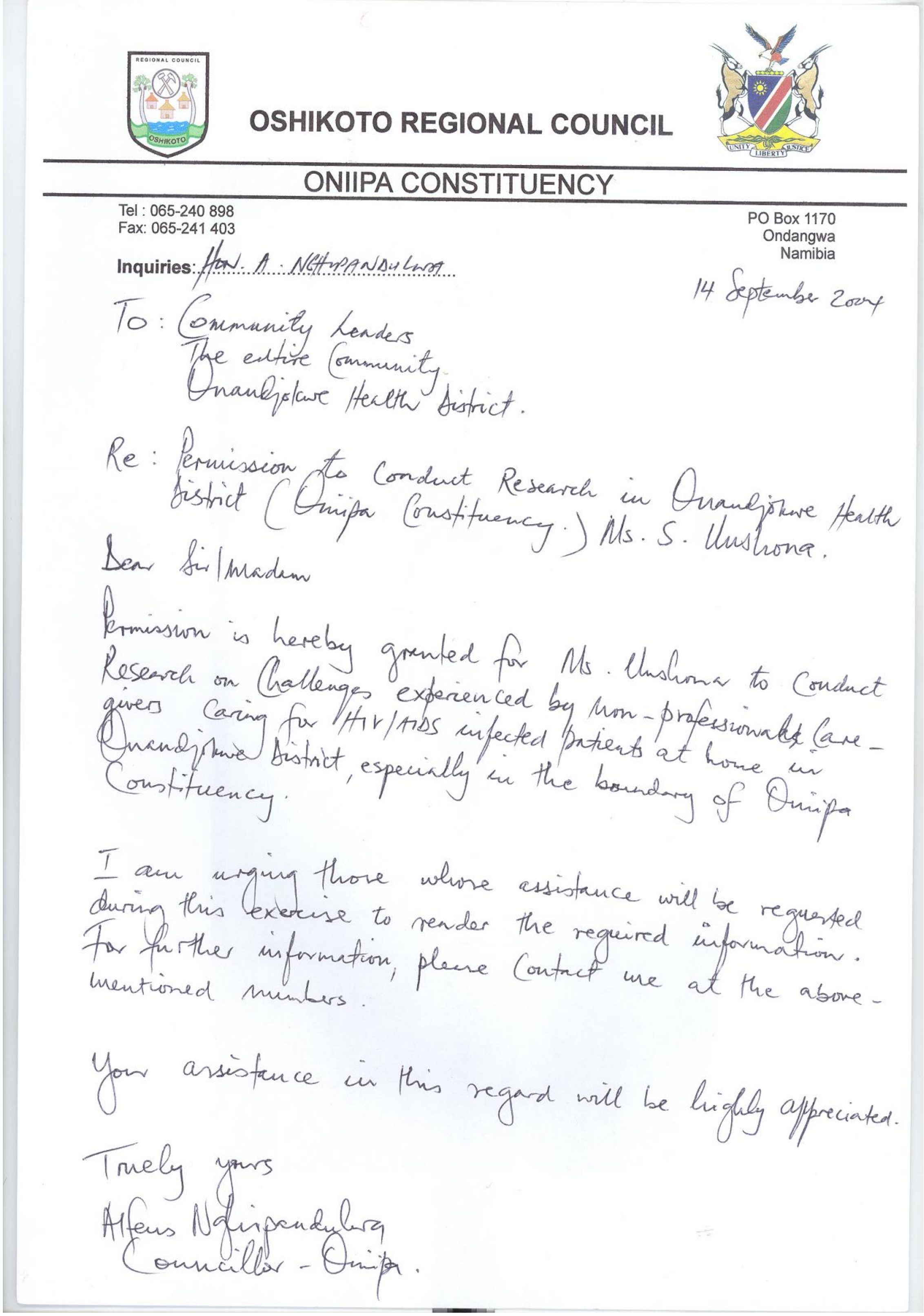
Tshikarepo A. Andjamba
Chief Regional Officer
Oshikoto Region

OSHIKOTO REGIONAL COUNCIL
04 OCT 2004
P.O. BOX 1116
TSUMEB

All official correspondence must be addressed to the Regional Officer

ANNEXURE G

LETTER OF PERMISSION TO CONDUCT RESEARCH IN ONIIPA CONSTITUENCY



OSHIKOTO REGIONAL COUNCIL

ONIIPA CONSTITUENCY

Tel : 065-240 898
Fax: 065-241 403

PO Box 1170
Ondangwa
Namibia

Inquiries: Hon. A. NGHIPANDULWA

14 September 2004

To: Community Leaders
The entire Community
Onandjokwe Health District.

Re: Permission to Conduct Research in Onandjokwe Health District (Oniipa Constituency.) Ms. S. Uushona.

Dear Sir/Madam

Permission is hereby granted for Ms. Uushona to Conduct Research on Challenges experienced by non-professionals Care-givers Caring for HIV/AIDS infected patients at home in Onandjokwe District, especially in the boundary of Oniipa Constituency.

I am urging those whose assistance will be requested during this exercise to render the required information. For further information, please Contact me at the above-mentioned numbers.

Your assistance in this regard will be highly appreciated.

Truely yours

Alfeus Nghipandulwa
Councillor - Oniipa.

ANNEXURE H

RESEARCH

QUESTIONNAIRE

12 May 2004

TO: **ALL NON-PROFESSIONAL CAREGIVERS**
ONANDJOKWE HEALTH DISTRICT

SUBJECT: **Research on challenges experienced by non-professional caregivers caring for HIV/AIDS-infected patients at home in Onandjokwe Health District in Namibia**.

I am Selma Ingandipewa Uushona, a registered nurse and lecturer who works at Oshakati Regional Health Training Centre for the Department of Community Health Nursing Science.

I am also a Master's degree student (student number 8901376) at the University of Namibia and am currently conducting research on **Challenges facing non-professional caregivers caring for HIV/AIDS-infected patients at home in Onandjokwe Health District** as part of the Master of Public Health degree requirements. The purpose of the study is to determine the challenges non-professional caregivers experience; to determine appropriate resources for supporting non-professional caregivers; and to recommend strategies to address the physical, moral, emotional and social needs of non-professional caregivers caring for HIV/AIDS patients at home.

This research project will be done under the supervision of Dr L Hoases and Mrs SN Shivute. Permission to conduct the research was granted by the following officers: Dr K Shangula, Permanent Secretary of the Ministry of Health and Social Services; Mrs S Mbandeka, PHC Supervisor for Onandjokwe Health District; Hon A Nghipandulwa, Councillor for Oniipa Constituency; and Hon V Kamanya, Governor of Oshikoto Region.

The questionnaire will be handed personally to respondents and will be completed in the presence of the researcher. The questionnaire is in English (the official language) but to accommodate better understanding, the questions will be translated into the Oshindonga language.

Respondents will have to complete the question according to their availability. Your opinion will represent the opinions of other non-professional caregivers like yourselves. The questionnaire will take 30 to 60 minutes to complete.

Could you please grant me a few minutes of your time to complete the questionnaire?
Thank you in advance.

Uushona Selma Ingandipewa
PO Box 901
ONDANGWA
Namibia

Contact numbers:

(065) – 245941 (home)

(065) – 2233000 x 3126 (work)

(264) – 812754939 (cell-phone)

SECTION A

DEMOGRAPHIC INFORMATION

INSTRUCTIONS:

- Please tick the appropriate box:

1. **Sex**
    1. Female ☐
    2. Male ☐

2. **Age**
    1. 15 – 31 ☐
    2. 32 – 48 ☐
    3. 49 – 65 ☐
    4. 66 + above ☐

3. **Marital status**
    1. Single ☐
    2. Married ☐
    3. Widow ☐
    4. Divorced/separated ☐

4. **Level of education (Tick the highest level of education).**

1. No formal education ☐
2. Primary education ☐
3. Secondary education ☐
4. Tertiary education ☐

5. **Do you belong to any religion?**

Yes ☐

No ☐

6. **If yes, which religion do you belong to?**

1. Roman Catholic ☐
2. Lutheran (ELCIN) ☐
3. Anglican ☐
4. Other (specify)

____

7. **Types of accommodation of respondent.**

1. Traditional house ☐
2. Brick house ☐
3. Informal settlement ☐

4. Other (specify)

____

8. **Means of communication**

1. Telephone ☐
2. Cell-phone ☐
3. Media, eg radio ☐
4. Correspondence, eg letters ☐
5. Other (specify) ☐

____

9. **Employment status**

1. Unemployed ☐
2. Formal. Employed ☐
3. Self-employed ☐
4. Subsistence farmer ☐
5. Other (specify)

____

____

SECTION B

This questions relate to the objective of describing the profile of home-based caregivers, determining the knowledge of caregivers, explaining protective measures used by caregivers of HIV/AIDS patients, and exploring the personal experiences of caregivers of HIV/AIDS-infected patients in Onandjokwe Health District.

10. **How many people are living in your household?**

    1. 1 – 5 ☐
    2. 6 – 10 ☐
    3. 11 – 15 ☐
    4. 16 – 20 ☐
    5. 21 and above ☐

11. **How many of those people are children under five years?**

    1. None ☐
    2. 1 – 3 ☐
    3. 4 – 6 ☐
    4. 7 – 9 ☐
    5. 10 – 12 ☐
    6. 13 and above ☐

12. **How many children are between the ages of 6 and 18 years?**

1. None ☐
2. 1 – 2 ☐
3. 3 – 4 ☐
4. 4 – 6 ☐
5. 7 – 8 ☐
6. 9 and above ☐

13. **How many people in your household are working?**

1. None ☐
2. 1-2 ☐
3. 3-4 ☐
4. Other (specify)

____

14. **What is the monthly salary of each person?**

1. Less than N$500.00 ☐
2. NS501.00 – N$1999.00 ☐
3. N$2000.00 – N$2999.00 ☐
4. Other figures (specify)

____

15. **Does the household have any income generating activities?**

1. Cuca shop ☐
2. Supermarket ☐
3. Informal selling (meat, baskets, clay pots, old clothes, traditional food, etc.) ☐
4. Farm products (Mahangu, pumpkins, mealies, cattle, pigs and goats) ☐
5. Other (specify)

____

16. **Mode of transport frequently used by non-professional caregivers**

1. Walking ☐
2. Public transport ☐
3. Donkey cart ☐
4. Own car ☐
5. Other (specify)

____

____

17. **What means of transport do you use to get to a health facility?**

1. Public transport, e.g. taxi ☐
2. Own car ☐

3. Donkey cart ☐

4. Other (specify)

____

18. **How far do you stay from the health facilities?**

1. > 5km ☐
2. 5 - 9km ☐
3. 10 - 14km ☐
4. 15 - 19km ☐
5. 20 - 24km ☐
6. < 25km ☐

19. **What is HIV?**

____

____

20. **What is AIDS?**

____

____

21. **How can one get HIV/AIDS? Please mention the mode of spread.**

____

____

____

22. **What are the signs a person may have when he or she is infected with HIV/AIDS? (Please mention them.)**

____

____

____

____

23. **Please tell me how HIV/AIDS can be prevented?**

____

____

____

____

24. **Is there a cure for HIV/AIDS?**

1. Yes ☐
2. No ☐

25. **Does the patient accept you as the caregiver?**

1. Yes ☐
2. No ☐

26. **What type of care do you provide?**

1. Physical care ☐
2. Psychological care ☐
3. Socio-economic care ☐
4. All the types of care mentioned above ☐
5. Other (specify)

____

27. **Do you care for the patient for the whole day?**

1. Yes ☐
2. No ☐

28. **If your answer is no, who else is assisting you in caring the patient?**

____

____

____

29. **How does caring for a person with HIV/AIDS affect you?**

____

____

30. **Do you use protective measures when caring for the HIV/AIDS-infected patient?**

1. Yes ☐
2. No ☐

31. **What type of protective measures do you use? Please mention them.**

____

____

____

32. **If your answer is no, what is your reasons for not using protective measures?**

____

____

____

____

33. **How frequently do you use protective measures when caring for HIV/AIDS-infected patients?**

1. Not use them at all ☐
2. Use them always ☐
3. Use them sometimes ☐
4. Other (specify)

____

34. **Why is it necessary to use protective measures when caring for patients with HIV/AIDS infection (please indicate your reasons)?**

____

____

35. **If you use gloves when caring for HIV/AIDS-infected patients, who provides you with gloves?**

1. Health facility ☐
2. Buy from private pharmacy ☐
3. Donation by NGO ☐
4. Other (specify)

____

36. **Please tell me how you handle and discard soiled materials, e.g. secretions, vomit, faeces and blood.**

____

____

____

37. **How do you manage to keep a weak patient who is suffering from diarrhoea dry?**

____

____

____

38. **Do you own a home-based care kit?**

1. Yes ☐
2. No ☐

39. **How do you use it? (Please explain.)**

____

____

____

40. **If you do not have a home-based care kit, what else do you use?**

____

____

____

41. **Is the patient on any medical treatment? Mention it.**

____

____

____

42. **Who is responsible for keeping and giving medication to the patient?**

1. Patient himself/herself ☐
2. Family members ☐
3. Volunteer ☐
4. Friend ☐
5. Neighbour ☐
6. Other (specify)

____

43. **Does the patient comply with the treatment regime and take the medication as prescribed in the correct dosage.**

1. Yes ☐
2. No ☐

44. **How do you experience caring for HIV/AIDS-infected patients?**

1. Enjoy ☐
2. Demanding ☐
3. Exhausting ☐
4. Challenging ☐
5. Other (specify)

____

45. **Do you face problems in caring for HIV/AIDS patients at home?**

1. Yes ☐
2. No ☐

46. **If yes, what problems do you face in caring for HIV/AIDS patients at home?**

____

____

47. **Are you coping with caring for the HIV/AIDS-infected patient at home?**

1. Yes ☐
2. No ☐

48. **If yes, how do you cope?**

1. Talk to a family member ☐
2. Talk to a friend ☐
3. Go for counselling ☐
4. Have an alcoholic drink ☐
5. Keep quiet ☐
6. Other (specify)

____

49. **What type of spiritual care do you render to critically ill patients at home? (Please describe)**

____

____

50. **Who is consulted to render spiritual care to terminally/critically ill patients who are facing the last stage of life?**

1. Pastor ☐
2. Psychologist/counsellor ☐
3. Nurse ☐
4. Other (specify)

____

51. **Explain how you care for the patient who is facing the end of his/her life.**

____

____

____

SECTION C

The questions relate to the objective of describing the profile of caregivers and determining the knowledge and type of support provided to HIV/AIDS-infected patients by caregivers.

52. **Did you have training in home-based care?**
    1. Yes ☐
    2. No ☐

53. **Who was responsible for your training?**
    1. Katonyala ☐
    2. ELCIN AIDS Action ☐
    3. Catholic AIDS Action ☐
    4. TKMOAMS ☐
    5. Other (specify)

    ____

54. **For how long did you train? (Duration of your training)**
    1. One week ☐
    2. Two weeks ☐
    3. Three weeks ☐
    4. Four weeks ☐

5. Other period more than four weeks (specify)

____

55. **What types of support system are available in your community? (Please mention them)**

____

____

____

____

____

____

____

____

____

____

56. **How does the support system assist you in caring for HIV/AIDS patients at home? (Please elaborate)**

____

____

____

____

SECTION D

The questions relate to the objective of identifying the type of support provided to caregivers; strategies needed to address physical, moral, emotional and social needs of the caregivers; in caring for HIV/AIDS patients at home.

57. **What suggestions can you make to support caregivers in caring for HIV/AIDS patients at home?**

____

____

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