PERCEPTIONS AND ATTITUDES OF FAMILY MEMBERS OF PEOPLE LIVING WITH HIV AND AIDS TOWARDS COMMUNITY CAREGIVERS

by

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I, **LUZILE FLORENCE NZIYANE,** declare that the Dissertation *PERCEPTIONS AND ATTITUDES OF FAMILY MEMBERS OF PEOPLE LIVING WITH HIV AND AIDS TOWARDS COMMUNITY CAREGIVERS* is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete reference.

Ms LF Nziyane **Date**

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ABSTRACT

The escalating number of people infected by HIV and AIDS poses a challenge to current resources both at the hospital and household level. Community/Home based care is a viable option in response to the scourge of HIV/AIDS to compliment secondary and tertiary care as well as providing support to affected families in coping with the stress of caring for their terminally ill family members. This study explored the effectiveness of the implementation of Community/Home based care services by focusing on three sites at Bushbuckridge i.e. Cunningmore, Maviljan and Hluvukani.

Findings revealed that family members were satisfied to have community caregivers entering their homes to provide care and support to their AIDS ill family members. Significant barriers were highlighted by families and community caregivers that hinder effective implementation of the programme, for instance, cultural sensitivity. The study proffered recommendations on how to deal with these issues.

Key terms:

HIV and AIDS; Community/home based care; Community caregivers; Care giving; People living with HIV and AIDS; Extended family; Perceptions; Attitudes; Support; Satisfaction.

CHAPTER ONE

INTRODUCTION, PROBLEM STATEMENT AND OUTLINE OF THE STUDY

1.1 INTRODUCTION

South Africa is now entering its 2nd decade of its democracy. Just as the country entered into drawing up a new South African Constitution with the advent of democracy and attempts to transform the country, the beginnings of the HIV & AIDS pandemic were being noticed because the patterns of mobility were changing. Since there is no cure as of today for this pandemic, hospitals do not cope with the escalating number of AIDS ill patients. Care and support to people living with HIV & AIDS became a huge burden to health workers. A local response to provide care and support to people living with HIV & AIDS at the comfort of their own home sought for Community/Home based care progammes (Schietinger 1993:49).

Community / Home based care is defined by the World Health Organization (1992) as:

> “The provision of health and welfare services by formal and informal caregivers in the home of the patient in order to promote, restore and maintain patient’s maximal level of comfort. It provides an alternative to institutional care, which received greater emphasis with the advent of HIV & AIDS. It addresses several problems including hospital overcrowding; high cost of institutional care, and shortage of resources e.g. hospital bed, staff…”

The National Departments of Social Development and Health in South Africa embarked on funding community / home based care programs to provide care and support to terminally ill patients at home. Monitoring and evaluation of these programs is a joint effort of provinces and the community in which the program is implemented.

The community/home based care programs are initiated in partnership with the community, of which the community plays a leading role. They are situated within the community and are run by a team of volunteers with the following portfolios: project manager, program coordinators and community caregivers. Four programs are generally identified in each community/home based care site i.e. orphans and vulnerable children's program; program for people living with HIV & AIDS; poverty alleviation program; and capacity building program. Community caregivers are the flagships of these sites. Their salient role is to visit families to provide care and support to people infected or affected by HIV & AIDS. They receive referrals of patients from local hospital, clinics, Department of Social Development and other state departments, welfare organisations, and the community itself. In terms of monitoring and evaluation, the executive committee manages these sites. The project manager also compiles monthly reports which are submitted to the Department of Health and Social Development's district offices for monitoring purposes. The reports include progress made, future plans and challenges. Some of the challenges mentioned in these reports indicated that some of the families which the community/home based care programs were working with do not allow the community care givers to visit their ill family members. Although the local clinics had referred the patients to the community/home based care sites, these families did not want the community caregivers to enter their homes to provide care to the patients. This is what motivated this study.

1.2 PROBLEM STATEMENT

Provision of care and support to people living with HIV & AIDS through community/home based care initiatives is seen as an achievement in the fight against the pandemic. Moreover, reports indicate the increasing number of established community/home based care in Provinces. Targets had been set by Districts to fast track the process of scaling up these community/based care services. The HIV & AIDS program in the Limpopo Province is coordinated in partnership with a coordinator from the Department of Health and a coordinator from the Department of Social Development to curb duplication of services. An integrated approach is used in which the coordinator from the Department of Health monitors the community/home based care services pertaining to the health issues of the patients; while the Department of Social Development’s coordinator monitors services related to the social welfare issues of the patients as well as orphans and vulnerable children.

How immediate family members accept the community/home based care initiatives is a question to be answered. Ndaba-Mbatha (2000:219) indicates that many studies have focused on the patient but very few on their families and needs. Project managers of the community/home based care programmes hold monthly meetings with HIV & AIDS coordinators from both the Department of Health and the Department of Social Development where issues pertaining the implementation of the community/home based care are tackled. From these meetings and according to reports compiled by these project managers, they experience challenges of community caregivers’ provision of care and support thwarted by immediate family members of people living with HIV & AIDS. Some of the challenges alluded to were families denying caregivers access to their homes when they conduct home visits to provide care and support to people living with HIV & AIDS. Some family members do not assist the community caregivers when they bathed their relatives. Community caregivers do not visit the same patient on a daily basis because of the high caseload of patients they are having and the diverse needs of these patients i.e. some are residing alone with very young children and therefore need regular visits by the community caregiver. With regard to patients residing with extended families, it is therefore important that family members work together with community caregivers with the provision of care and support to the patients to ensure continuity of service provision by family members when the community caregiver is not visiting the patient. However, from these monthly meetings, some project managers alluded that some community caregivers, during their next visit, found the patient unattended by family members and developing bedsores from this negligence. A shocking case was reported by the Hluvukani site, where the patient died during the night and the family did not call the undertakers but waited till morning to report to the project manager that *“ Your person has died, come and take her to the mortuary ”*. Despite attempts made by the project manager to remind the family of their responsibility towards the deceased. They refused to take responsibility indicating the fact that since the deceased was receiving care from the site and it is therefore the site’s responsibility to bury her. The matter was finally resolved during the afternoon through the intervention of the local social worker.

1.3 GOALS AND OBJECTIVES

1.3.1 Goal

To establish the requirements for effective implementation of community/home based care services to people infected or affected by HIV & AIDS.

1.3.2 Objectives

(i) To assess the level of satisfaction of family members of people living with HIV & AIDS towards community/home based care services.

(ii) To unpack salient issues underlying the perceptions and attitudes of family members of people living with HIV & AIDS towards community caregivers providing care to these patients.

(iii) To proffer recommendations concerning policy of community/home based care program and its impact in the community for program development.

1.4 ASSUMPTIONS

Attitudes of immediate families of people living with HIV&AIDS are positively related to the approach of community caregivers when entering the homes of the people living with HIV&AIDS. The more the community caregivers involve the immediate families in providing care to the AIDS ill family member, e.g. bathing, the more the immediate families will allow the community caregivers to enter their homes to provide care to the ill family member; and will continue providing care and support to the patient during the absence of the community caregiver.

1.5 RESEARCH METHOD

1.5.1 Research design

An exploratory research design has been chosen for the research based on the fact that the area under study has not been well researched in the social work field. There are no sound social work theories regarding the perceptions and attitudes of family members of people living with HIV&AIDS towards community caregivers. Both quantitative and qualitative research methods have been used for the study to explore issues related to the community/home based care programme as experienced by both family members and community caregivers.

1.5.2 Research instrument

Two separate standardized questionnaires were compiled and administered by the researcher for the research. The first questionnaire (see Appendix A) focuses on the community caregivers to obtain information regarding their level of training, type of services they provide to people living with HIV&AIDS and their families, as well as the involvement of family members in providing care and support to their ill family members. The second questionnaire (see Appendix B) focuses on family members of people living with HIV&AIDS to explore how they perceive and accept the community/home based care programme. Both open and closed-ended questions were used for both questionnaires. Details on the research instrument will be discussed in section 3.3.

1.5.3 Sampling

Two samples were drawn from three community/home based care sites that are providing care and support services to people living with HIV&AIDS and their families, namely, Cunningmore, Hluvukani, and Maviljan. The two samples are as follows:

1.5.3.1 Sample 1: Family members of people living with HIV&AIDS

Fifty families (n=50) were selected through stratified and systematic sampling methods to ensure that all families with ill patients have an equal opportunity of being selected. Families were first grouped according to subsets (that is villages and thus spoken languages) by using a stratification approach in conjunction with systematic sampling to ensure that there is a fair representation of all fourteen villages and all three spoken languages in the study site. Each family was allocated a number and every second family was selected. The first family was selected randomly to curb human bias.

1.5.3.2 Sample 2: Community caregivers

Fifty community caregivers (n=50) were selected for the research. The sample of family members, as mentioned above, was used to determine the selection of the community caregivers sample. For each family that was selected, its community caregiver was subsequently selected to ensure that issues related to the mutual perceptions of family members and community caregivers to community/home based care are explored.

1.5.4 Data gathering

Face-to-face interviews were conducted to collect data from both interviews with families and community caregivers. Interviews with families were conducted in their homes. One interview was conducted per family. Questionnaire 2 (see Appendix B) was used to collect data from the families. One questionnaire was used per family. Responses were recorded in the space provided for each question. Note books were used to record responses that were too long to be recorded on the questionnaires.

Interviews with community caregivers were conducted at each community/home based care site, in a closed room provided by the project managers. Questionnaire 1 (see Appendix A) was used to collect data from the community caregivers. One interview was conducted per community caregiver. See section 3.5 for more details on data gathering.

1.5.5 Data presentation

Quantitative and qualitative data is presented in the form of tables and narrative manner. Inter-related data emerging from the two separate questionnaires is presented in an integrated manner to provide comparative responses from both the family members and the community caregivers.

1.6 DEFINITIONS OF CORE TERMS

1.6.1 Immediate family/extended family

Duvall & Miller (1985:7) define extended families as families that include relatives in addition to the nuclear family, i.e. grand parents, uncles, aunts, nieces or nephews. In the context of the study, the extended / immediate family is defined as above. Immediate family or extended family refers to any member of the family as elaborated above, with which the person living with HIV & AIDS resides within the same yard. A yard refers to the space of land the dwelling is built on. In Bohlabela district, most people reside with their extended families in the same yard. The concepts ‘immediate family and extended family’ are used synonymously and inter-changeably with “family members” in this study.

1.6.2 People living with HIV&AIDS

People living with HIV & AIDS refer to individuals infected with the human immunodeficiency virus who are terminally ill and are receiving care from community caregivers in the patient’s home. They are often referred to as “patient”, “AIDS patient” or “ill family member” in this study.

1.6.3 Community caregivers

Community caregivers refer to formal caregivers attached to a community/home based care site, providing care to patients who are not related to them. These caregivers have signed contracts with the sites and are monitored by the managers of the sites.

1.6.4 Community/home based care programme

Community/home based care programme refers to a community programme funded by the Department of Health and the Department of Social Development and/or other donors, with community caregivers providing home-based care and support services to people infected and affected by HIV & AIDS. The concept is often referred to as “site” or “center” in this study.

1.7 DURATION OF THE STUDY

The study commenced in 2002 and was concluded in 2005. The researcher began collecting data from the three community/home based care sites i.e. Hluvukani, Cunningmore and Maviljan from August 2004 to September 2004.

1.8 SHORTCOMINGS OF THE STUDY

The study had the following shortcomings:

- The interviews with the family members were conducted at the respondents’ homes where a lot of interruptions occurred. Some families had very ill family members who were sometimes calling for the attention of the persons who were being interviewed.
- Certain families could not participate in the study due to sudden death of their AIDS ill family members.
- It is assumed that families’ loyalty towards the community caregivers might hamper honest responses from families especially because of the benefits that come with the

community caregivers, for example, relieving the family with the burden of care, the provision of food parcels and the immediate attention they got from local clinics.

- It is assumed also that the interviews with the community caregivers might not elicit honest responses for they would not want to jeopardise their standing with the Project Managers, especially since the interviews were conducted at the community/home based care sites.

1.9 OUTLINE OF THE STUDY

This thesis is divided into five chapters, namely:

- Chapter 1 contains the introduction, the problem statement, definitions of major concepts used in the study, the goals and objectives of the research, duration of the study, assumptions, and limitations of the study.
- Chapter 2 contains the literature study on HIV&AIDS and community/home based care.
- Chapter 3 shows how the research process unfolds from the research design used, research instrument, the actual method of collecting data, the sampling procedure for the two samples, to the data analysis. The brief background on the site studied i.e. Bushbuckridge municipality is also outlined in this chapter.
- Chapter 4 presents the findings of the research.
- Chapter 5 concludes the research and provides recommendations for this dissertation.

CHAPTER TWO

HIV&AIDS AND COMMUNITY/HOME BASED CARE

2.1 INTRODUCTION

This chapter highlights previous research conducted in the area of community/home based care programmes and HIV&AIDS. It seeks to establish whether previous research was conducted in relation to immediate families' acceptance to community/home based care services, pointing to general agreements and disagreements among the previous researchers.

According to Rubin & Babbie (1997:106) the literature review is the most important step in the entire research study since it helps researchers to investigate whether the research question has been thoroughly researched so as to fill the gap rather than reinventing the wheel.

This chapter will, from previous research, identify the needs of immediate families towards community/home based care services. It also seeks to identify, if any, lessons learned from, and the challenges of, providing community/home based care services for people living with HIV&AIDS and their immediate families.

2.2 HIV/AIDS: Overview

2.2.1 HIV/AIDS origin

Debates about the origin of HIV continued to provide answers of where the virus came from while the virus was spreading around the world.

The first case of an acquired immune deficiency syndrome remains a challenge on when it was reported and where it was reported. Most studies (Moss 1992:4; Richardson 1987; Whiteside & Sunter 2000:1; Jager 1988:17 & Dossier 1992: vi) indicate that the first case was reported in the United States in 1981. The increase of pneumocystis carinil pneumonia cases and Kaposi Sarcoma cases in certain groups of people, namely injecting drug users, Haitians and homosexuals, propelled scientists to do research. It was discovered that the infectious agent is transmitted through blood and sexual contact. After countless laboratory research world wide, the human immunodeficiency virus was discovered and was found to be the cause of AIDS.

Lightfoot (1997:1) and Whiteside & Sunter (2000:47) indicate that in South Africa, the first case of the acquired immune deficiency syndrome was recorded in the February 1982 edition of the South African Medical Journal.

According to Daigle, Lasch, McCluskey & Wancho (1999:2-3), HIV belongs to the class of viruses known as retroviruses. These viruses have the “ability to convert their genetic ribonucleic acid (RNA) to deoxyribonucleic acid (DNA) by means of enzyme known as reverse transcriptase”. Retroviruses are known to cause diseases such as AIDS.

AIDS was not an issue during the early 1980’s since it only killed less people i.e. about 100,000 a year world wide as compared to Malaria which killed about one million people per year and about 12 million died from heart and other cardiovascular diseases. The overturn of death rates caused by the Acquired Immune Deficiency syndrome and the increased rate of the spread of HIV was so alarming that more attention was given to the investigation of this infection (Dossier 1991:v &Moss 1992:5). Barnett & Whiteside (20022:4) concur with these researchers by indicating that at first the pandemic was not given much attention as it currently does because it is not the first epidemic disease to have spread around the world and between diverse societies. Plague is one epidemic which occupied a special and horrific place in the European countries. Although it has left Europe and North America, it still remains endemic in some poorer countries. However, AIDS is the first epidemic of globalization, because of the rapid rate it is spreading. It succeeded in making people around the world to join efforts to mitigate its threats and implications. It is so far the only epidemic to have a dedicated United Nations organization i.e. UNAIDS.

2.2.2 The current situation

Barnett & Whiteside (2002: 9); Daigle et al (1999: 2) and Whiteside & Sunter (2000:2) indicate that the pandemic has currently been reported in all countries and has hit hardest in Africa south of the Sahara where it is still moving at a high speed.

According to Stadler (2001:1) & Department of Social Development (2002:1), South Africa has the second fastest growing epidemic in the world with nearly 5 million people already infected. Over 20% of children have lost one or both parents. This is making it impossible for hospitals and clinics to cope with the escalating number of patients. It is also impossible for the extended families to absorb the high number of orphaned children into their homes. Community based care is seen to be a viable option as an intervention to this scourge.

Currently the country has a high proportion of children who are not cared for regularly by either parent, because of the displacements of people during the apartheid era. The pandemic poses itself in this already fragile family environment. Since most orphans are being cared for by their relatives, especially the grandparents, this implies that these orphans are facing a situation of being orphaned twice i.e. when the grandparents die. Most children are becoming heads of the families because their parents have died (Whiteside &Sunter 2000:80). Desmond & Gow (2001:15) further indicate that orphaned children who are infected by HIV/AIDS will need more care as compared to those who are not infected.

HIV data in South Africa is drawn from surveys of specific groups. During the early years of the discovery of the disease, the specific groups included blood donors, sexually transmitted infections clinic attendees, people with tuberculosis, and women attending antenatal clinics. Currently the data is drawn from women attending the antenatal clinics. This is done on an anonymous and unlinked manner. This means that women who provided their specimen cannot be identified for their results. However, the accuracy of the statistics remains a challenge (Whiteside & Sunter 2000:32-33).

Currently, there is no known cure for HIV/AIDS. However, much research has gone into the search for a cure and a vaccine, although none has been discovered so far. Whiteside & Sunter (2000:21) indicate that the antiretroviral drugs and other related drugs are being administered to prolong the lives of people infected with HIV/AIDS.

The South African Government's Operational Plan for Comprehensive HIV and AIDS Care and Treatment aims to provide HIV treatment and care to the estimated 1.4 million South Africans within five years (South African National Department of Health, 2003) . This ambitious roll out will not only improve the lives of those living with HIV&AIDS but also has implications for the progression of the HIV epidemic.

2.3 HIV/AIDS and the community

Dossier (1992:45) quotes from the report on the impact of the pandemic in East and Central Africa that: "AIDS must be regarded as a community crisis not simply an individual problem; one which is likely to adversely affect entire communities by threatening their collective ability to cope".

2.3.1 HIV/AIDS and social development

"AIDS will alter the history of many of the world's poorest societies", says Barnett & Whiteside (2002:21). These two authors continue to indicate that in sub-Saharan Africa, which is the hardest hit by HIV/AIDS, a child born in the worst affected countries between 2005 and 2010 can be expected to die before reaching his or her 40th birthday. Without effective treatment, people infected with HIV develop AIDS which results in death. In Abidjan and Tanzania, AIDS has been identified as the major cause of death in adults between the ages of 15 to 59.

Barnett &Whiteside (2002:73-77) indicate that HIV/AIDS also impacts negatively on fertility. The number of births is reduced when women die before reaching the end of their childbearing years, as well as through prevention intervention where couples use condoms as a preventative method for not contracting HIV. Children born of infected mothers are at risk of contracting the virus and have a very low life expectancy. This implies that the population growth is impacted negatively by the pandemic.

According to Dossier (1992; 45) & Modly (1997: 173-176), the pandemic threatens the extremely important norms and values of a community. For example, the elderly and the children are faced with the role of caring for the sick adults. Elderly people are faced with the role of rearing their orphaned grand children. Research done by UNICEF as quoted by Dossier (1992:45) indicates that: “there will be 3-5million orphans in African countries by the end of the 21st century”. Traditionally, these orphans are reintegrated with the extended families; but because of the escalating number of AIDS deaths and poor socio economic standards, children will head many households. Children growing up without parents and badly supervised by relatives are more likely to engage in criminal activity. The study conducted in Kenya about the plight of orphans and their caretakers indicated that families with foster orphaned children live below the poverty line. As nuclear and extended families are hit by the AIDS pandemic, the need to compliment these traditional approaches by community based care programmes is imperative (Whiteside & Sunter 2000:95 and WHO 1992: 17).

Orphaned children who lose a parent due to AIDS suffer loss and grief like any other orphan. However, their loss is exacerbated by stigma and discrimination by communities. Whiteside & Sunter (2000:95-96) indicate that most of these orphans have witnessed the suffering of their dying parents and some have experienced the actual death of their parents because of AIDS patients being cared for at home. It is found that some of the orphaned children have cared for their dying patients at home. The psychological impact of witnessing a parent dying of AIDS can be more intense than children whose parents did not die of AIDS.

Dossier (1992: 47) highlights that the AIDS pandemic also put a strain on social coping systems since the communities face a task of contributing towards continuous funeral expenses of neighbours and relatives as well as care for the sick and orphaned children.

In her study on the response of communities towards HIV/AIDS, Birdshall (2003) found that the involvement of civil society organisation and faith-based organisation is noticeable because of the increased number of these organisations providing care, support and information on prevention of HIV/AIDS. HIV prevention activities were the most common intervention followed by the care and support interventions. Funding remained a challenge for most of these organisations. For community response to be maximised, these community organisations needs to be developed, capacitated and supported. Bhalla (2004) also indicates that community care centers exist in communities to take care of the sick. However, this method was seen to be expensive since it required professional and full-time staff to provide the sick with full-time services (Bhalla 2004).

Mashiapata (2004:79) indicates that traditional leaders are a key figures in the strategy to access the rural populous. In most cases people in the rural areas accept messages and services, provided the messages are from the traditional leaders or there is sufficient evidence to proof that there has been consultation with the traditional leaders.

Ngcobo (2004) in her research on empowering community based care organisation with skills for caring and supporting children and families infected and affected by HIV/AIDS, she indicated that community based care organisations were well positioned to play a strategic role in the fight for HIV/AIDS because of their proximity to the communities they were serving.

It is clear from the preceding paragraphs that communities are affected by the HIV/AIDS and are taking responsibilities in the fight to mitigate the impacts of the disease. A community based care approach is seen to be an acceptable and affordable approach to respond to the HIV/AIDS pandemic. However, the sustainability of the community based care programmes remains a challenge in terms of funding and capacity building.

2.3.2 HIV/AIDS and the socio-economic status of victims

Studies (Whiteside & Sunter 2000:32; Dossier 1992:20, 25&45 & WHO 1992: 16-17) indicate that the HIV/AIDS pandemic strikes adults who are mostly the backbone of the country's labour force and are usually between the ages of 25 and 49. These are people still in their reproductive years and are mostly breadwinners as well. These studies indicate that wealth is seen generally to equate health. Individuals who are infected by HIV and who are constantly sick are not productive as individuals who are not infected with the virus. Women are the mostly infected group and fall ill earlier that men.

Whiteside & Sunter (2000:85-88) indicate that the illness and death of productive people has a consequent effect on productivity. HIV/AIDS also affects negatively the economic status of individuals and families. With a person infected by HIV/AIDS means that the distribution of resources is affected in the sense that some of the savings will be spend on medication and special food and so on. For individuals who do not have such savings, the burden of care rest with the state to provide such care and thus impacting on the economy of the state. Job losses also increase the ratio of dependency on the state and the generosity of the community to help fund HIV/AIDS relevant non-governmental organisations (NGO’s).

Hanifa, Mthombeni, Dwadwa, Charalambous, Churchyard, Grant & Fisher (2004) in their study on the impact of HIV/AIDS on the employees of Anglo American found that the pandemic has a severe effect on the mining industry of South Africa. There was lots of absenteeism by the employees due to HIV/AIDS. This has an adverse effect on the production. Similar findings were tabulated by Shisana et al (2004) in their study on the impact of HIV/AIDS for educators in South African schools. They found that educators who were infected by HIV/AIDS were the most to be absent from school.

The Constitution of the Republic of South Africa Act 108/1996: Sec 27 guarantees everyone the right to have access to health care services, sufficient food and water as well as social security. Disability grants are available to adult South African citizens who are incapacitated and unable to work due to illness or disability. A number of people with HIV/AIDS (PWAs) have accessed disability grants when they fulfil the criteria set down by the Department of Social Development. This also impacts on the economy of the country in the sense that the number of people requiring disability grants will increase tremendously because of the HIV/AIDS (Richter & Hardy 2004).

Many studies both nationally and internationally found that the administration of antiretroviral drugs has proven to prolong the lives of people infected with HIV/AIDS (Barnett & Whiteside 2002:329 and Bock, Boulle, Cloete & Cohen 2005). This means that workers can be kept at their working environment for longer. Richter & Hardy (2004) indicate that the question regarding whether infected people in the country with a high rate of unemployment can adhere to treatment, remains unanswered. Especially for patients who are receiving disability grants because these grants will be discontinued by the Department of Social Development when the patients become well when administering the antiretroviral drugs.

2.3.3 HIV/AIDS and poverty

Whiteside & Sunter (2000:91) say that: “The links between poverty and health are increasingly recognised and understood”. It is not clear whether AIDS is simply a disease of poverty, but most studies found that poverty is the conduit of the pandemic and it helps to drive the epidemic. This was also found by Shisana et al (2004) in their study on the impact of HIV/AIDS for educators in South African schools. They found that educators who were earning less were most infected by the pandemic. Although in the early stages of the pandemic, some of the rich were mostly infected because they had money to travel and to purchase sex. However the tide has turned and it is the poorer communities that are mostly hit by the virus.

Poverty significantly increases the likelihood of a number of unsafe sexual behaviors and experiences. It is important to note that poverty affects behavior in diverse and multi-faceted ways.Some of the women engage in unsafe commercial sex (prostitution) because of poverty. Studies (Hallman 2001; Shisana et al 2004 and Whiteside & Sunter 2000:91-92) indicate that orphanhood with poverty is also seen to be increasing the spread of HIV. Poor orphaned households were found to be the most infected by HIV. Female and male paternal orphans debut earlier sexually especially when they are coming from households headed by children where there is low discipline.

Daigle et al (1999:210-211) also indicate that the majority of people infected by HIV in the United States are young women who are poorly educated and have little resources. They have poor access to adequate health care, transportation, housing and food.

Whiteside & Sunter (2000:92) state that poverty is not only seen as a conduit for HIV/AIDS, the pandemic is also seen to be causing poverty. In effect, AIDS has the potential to push households that were not poor into poverty or households that were already poor deeper into poverty. As discussed in the preceeding paragraphs, when employees who are too ill to work are retrenched or medically boarded, they loose most of their benefits and have to spend their savings on medication and special diet. When such savings are exhausted they rely on the state. Currently state hospitals recognise that it is not appropriate to keep AIDS patient since there is no cure. Subsequently these patients are discharged from hospital to be cared for at home and thus placing an extra financial burden on the households.

2.4 Care of people with HIV/AIDS by extended families

According to Dossier (1992: 46) the definition of a family differs from culture to culture. Families range from a ‘nuclear family’ which comprises parents and children, to an ‘extended family’ which comprises parents, children, grand parents, aunts, uncles and other relatives. Studies (Gee & Moran 1988: 379; van Steijn 1989: 15 & Williamson, Smith & Burley 1987:1 & 150) concur that whatever the socio economic status of the family, it serves as the primary source of support to its members in times of need and crisis.

Daigle et al (1999:4-5) say that care in the home of the person with HIV/AIDS by family members occurs in a continuum. It begins when the person is diagnosed with the virus and it may continue throughout the course of the illness until the death of the person. Because the illness of the person with HIV is fluctuating and unpredictable, this means that family members must always be prepared to meet the person’s ever-changing needs.

According to studies (Dossier 1992:46-48; van Steijn 1989:19 & Gee et al 1988:390 & Schopper 1992:94), the fact that the HIV is transmitted sexually, threatens the health status of the family in the sense that couples infected by HIV can transmit the virus to their offspring. This creates a burden for the extended family, which has to care and support the couples and the offsprings who are sick and dying. The need to buy medicines and special diet for the ill family members puts a strain on the family budget, making it difficult for families to provide care.

Daigle et al (1999:211-212) indicate that families are faced with emotional pain of having an AIDS ill family member. They are confronted with a situation to anticipate the loss of the family member because there is no cure for the disease. Some families choose to deny that their family members are AIDS ill in order not to deal with the fears associated with the fatal disease.

Families face a challenge of disclosing a status of their HIV positive family member. This is often accompanied by a number of factors and emotions in considering the pros and cons of such disclosure. Some of the factors include fear of having to deal with shame and guilt of how the virus was contracted and fear of being ostracised and socially excluded. However, disclosure also relieves the family from the burden of carrying a secret and may openly explore interventions designed to fight the pandemic (Daigle et al 1999:206-207).

Although Williamson et al (1987:150) in their study on primary care of the elderly state that the family setting enables the patient to be more at ease and thus becomes more responsive; Sims et al (1995:6) & Ndaba Mbata (2000:219) indicate that caring for people with AIDS at home is problematic since the family members are not skilled to give the intravenous drugs and to provide counselling needed by these patients. Gee & Moran (1988:272) confirm these by indicating that family caregivers need to know how to protect the patient from further infections and how to protect themselves from contracting the virus while providing care. Daigle et al (1999:5) also indicates that for care in the home of the patient to be effective, patient and caregiver education is essential. As the disease progresses, complications such as memory problems and open wounds occur, hence education is essential for the success of safe and effective care in the home.

Studies (Gee & Moran 1988:280,379 & 381; Jager 1988:19 & 98; Richardson 1987:138 & Schopper 1992:94) indicate that the lack of knowledge of HIV/AIDS by family members makes it difficult to provide care for their ill family members because of fear of contagion.

Sims & Moss (1995:144-145) indicate that it is also difficult for a nuclear family where a mother has AIDS. The father will need support in caring for the children and maintaining the home as well, because giving up his job will probably have financial implications. The need for voluntary caregivers to work together with families is imperative. This is confirmed by van Steijn (1989:19) and Richardson (1987:138-139) that in a case of couples where one partner has been diagnosed HIV positive, it is difficult for the other partner to provide care because he/she has to face fears of his/her own potential HIV status.

In his study on the psychological impact of the HIV infection between the infected person and significant others, van Steijn (1989:9) found that significant others are also affected tremendously by the infection because people do not live in isolation but are existing within social systems. Studies (Gee & Moran 1988:380; Richardson 1989:131,133-134; Williamson et al 1987:152 Garfield 1996: 377-378 & Wrubel 1997:702) confirm that family members who provide care and support to their ill family members are affected emotionally. The burden of care they are faced with causes burnout and they also need bereavement support.

Modly (1997:173-176) says that some family caregivers to ill family members do not see themselves as caregivers but see this as a privilege and responsibility. They see themselves as showing love to family members.

2.5 Terminal care needs of people living with HIV/AIDS

Van Steijn (1989:11) in his study on newly diagnosed HIV positive persons, has found that the person has a tendency of redefining his personal and interpersonal boundaries, for example, to whom to disclose their HIV status and what to do with persons who are excluded from the secret (with fear of losing them) although they have the capacity to provide emotional or material support. It was also found that HIV positive persons often trust people who are not related to them such as doctors or counselors and whom they can disclose their HIV status. Richardson (1987:136) indicates that newly diagnosed HIV positive people hesitate to disclose to their family members because they feel that they might be a burden to them.

Research (Sims et al 1995:13) indicates that a high number of people infected with HIV are people who are productive in a society. Efforts to care and support these infected people will benefit the society because if they are given appropriate care and support they can live longer and be able to contribute to society.

Research (Jager 1988:18-19; Gee & Moran 1988:379; Molnos 1990: 22& Garfield 1996: 377-378) indicate that people with AIDS need care and are highly dependent on others. Care is imperative to a person with AIDS because it makes him/her feel visible and it helps him/her to cope with the disease. Patients with AIDS experience more psychosocial problems than patients suffering from other deadly diseases. Hence they need to talk to someone about how they are feeling. People trained in counselling or pastoral care workers are needed to help these patients because once diagnosed, the thought of death becomes an obsession and this can lead to depression. The intensity of such emotions depends on the social support the patients get.

Rochat, Stein, Richter, Buthelezi & Mkhwanazi (2005:89) indicate that depression is high amongst women attending ante natal services who are testing for HIV for the first time. This has implications for screening and treatment of depression in antenatal programs; where women are encouraged to test for HIV. This is of particular concern as depression is known to influence adherence to treatment programs. It is therefore important to meet the need for care and support for the people who are infected with HIV.

Searle, Williams & Homan (2004) also state that the common need identified by people infected with HIV was to have someone to provide emotional or spiritual support and counseling. This was followed by someone to assist with physical care that includes bathing, feeding, dressing and using the toilet as well as providing nursing care that includes pain management, treating wounds and taking medication. Assistance with household chores such as cleaning, cooking, shopping, running errands or gardening and someone to provide information and education or skills training were also deemed important.

2.6 Community home based care

The National Department of Social Development (2002:11) defines community home based care as strategy, which “enables the individuals, families and communities to have access to services within their homes and communities”. Teams of workers participate in this type of care, which includes the patient, family members, volunteers or caregivers, health workers and counsellors (Stadler 2001:2-3). The demand due to the pandemic causes overcrowding in hospitals and clinics hence community based care approach is sought for (Sims & Moss 1995:147).

In a study by Moss (1992:83), on palliative care it was found that at least 63% of Aids patients die at home and these patients prefer to die at home rather than in institutions. The surroundings are familiar to them and they feel at ease to be cared for by the people who are more close to them. These patients are able to communicate their last words with their family members.

Studies (Sims & Moss 1995:4-6 & 140, Williamson et al 1987:150& Jager 1988:171) show that when it is successful, care provided in the patient’s familiar surroundings (that is the patient‘s home), could produce the very best of terminal care. The patients have their own freedom and can behave as they wish. However there are other patients who are either living alone or are living with smaller children (that is under the age of eight). Refugee patients often have no family to care for them. In such cases, voluntary services from the community are essential.

Studies (Ndaba-Mbata 2000:219-221, Schopper 1992:94) on home-based care indicate that families of persons living with AIDS are not capacitated on how to care for their ill family members. Records of elderly who are diagnosed HIV positive indicate that transmission might have occurred during the process of care giving. This threatens the effectiveness of care being provided at home. Although involving volunteers/caregivers to assist families in providing care, families can reject it because it threatens the family's right to privacy and confidentiality. Families are facing a fear that disclosing of family secrets by the volunteers is possible

Selepe (2004:53) indicates that the involvement of communities enhance adherence of people living with HIV&AIDS to antiretroviral therapy. Support groups act as an enabler to encourage patients to take their medication as well as providing support to people living with HIV/AIDS.

Daigle et al (1999:271) indicate that culture plays an important role when providing care to patients at their homes. Culture has an influence on illness beliefs and behaviours, health-care practice, and the way in which the patients receive medical care. Respect of family cultural beliefs by community caregivers is imperative in home care because the patient's cultural practices will assume preference in their homes. "When the home health-care nurse enters the home of the patient, the patient from another culture will sense acutely the difference between them. The patient will have his or her own sense of illness and how to treat symptoms", says Daigle et al (1999:263-267). In order for home health-care nurses to work more effectively, it is imperative to be sensitive to cultural differences and work collaboratively with the patients and their families.

In their study on folk healers and the Haitians, Daigle et al (1999:271) found that many people living with HIV/AIDS preferred cultural remedies from folk healers rather than western medicines. People living with HIV/AIDS may prefer to go to a traditional healer because they will get a different diagnosis other than AIDS because they do not want to be diagnosed with HIV/AIDS.

2.7 Care giving and HIV/AIDS

Care is defined by the Oxford Dictionary as: “The process of looking after somebody or something, the providing of what somebody or something needs for their health or protection”. Richardson (1989:130-132) defines caring as an “activity” which is always carried out by women; because as a wife and a mother, the woman is expected to care for her children and family. Richardson continues to indicate that caring is accompanied by feelings of love and can also be seen as an obligation towards a person who is receiving the care.

The HIV/AIDS epidemic has meant that an increasing number of chronically ill people need assistance with care and support. Currently these services are available, albeit to a limited degree, from both formal and informal caregivers. However, few studies have explored the role of different caregivers in meeting the needs of people living with HIV/AIDS. In their study on exploring the role of family caregivers and home based care programmes in meeting the needs of people living with

HIV/AIDS, Searle et al (2004) found that the needs of people living with HIV/AIDS included to have someone to provide emotional or spiritual support (counseling). This was followed by someone to assist with physical care (bathing, eating, dressing, using the toilet) and nursing care (pain management, treating wounds, taking medication). Assistance with household chores such as cleaning, cooking, shopping, running errands or gardening and someone to provide information and education or skills training were also deemed important and cited by more than half the households.

While household caregivers provided the majority of physical care and assistance with household chores, formal caregivers provided the bulk of lay counseling, nursing care, information, transportation, and legal aid. On average household caregivers spend more time per week assisting the sick person than the formal caregivers.

Matsoga et al (2004) in their study on assessing home based care for people living with HIV/AIDS, found that caregivers are faced with multi-level challenges in performing their role. Caregivers have little knowledge and skills on how to support and care for people living with HIV/AIDS, both at the individual and organizational levels. Caregivers experiences physical & psychological burnout; the destruction of household economies and communities stigmatising and rejecting them.

Ngcobo (2004) in her study on empowering community based organisations with skills to best care for children and families infected and affected by HIV/AIDS, found that community based organisations needed skills and mentorship in order to be able to provide care to people living with HIV/AIDS.

Research (Richardson 1989:136-137 & 142 & Schopper 1992:94) indicate that stigma and discrimination associated with AIDS make it difficult for care to be effective. Neighbours and friends tend to isolate families caring for AIDS patients. Those providing care also needs support as carers because of the emotional burden associated with caring for an AIDS patient. Economic status and the additional workload of caring for an AIDS patient also inhibit effective care giving.

2.8 Stigma and discrimination

According to the Oxford Dictionary, the word ‘stigmatise’ means “to describe or consider somebody or something as very bad, worthy of extreme disapproval”. Discrimination is defined as treating a person or group differently (usually worse) than others.

Gee & Moran (1988:382) define stigmatisation as “the acrimonious labelling of individuals or groups who are perceived as grossly violating commonly held properties, values or morals”.

Research (Jager 1988:19-20) indicates that seventy six percent of AIDS patients in West Berlin were from the male homosexual group. Society regards homosexuality as immoral. The association of AIDS and homophobic judgements of homosexual people led to the disapproval of patients with AIDS. The fact that HIV is commonly found in people with multiple sex partners also led to the disapproval of AIDS patients, because society regarded this as being immoral (WHO 1992:20). It is apparent from this research that the stigmatisation and discrimination of people living with HIV/AIDS emerged as an acting out towards behaviour that was seen as unacceptable by members of communities. Although the pandemic has spread to people outside the parameters of what the community called “unacceptable behaviour”, as well as children born from mothers who are infected by the virus, discrimination and stigmatisation of people living with the virus as well as their families still occurs.

Research (Jager 1988:18; Gee et al 1988:280, 382-383; Dossier 1992:48; Olenja 1999:198 & Friedland et al 1996:16) indicate that both caregivers and patients with AIDS experience discrimination by friends and neighbours. Some AIDS patients are being stigmatised by their families. The fear of infecting others or being infected even though this is not possible through social contact, strengthens the sense of isolation.

Zungu et al (2004:45) in their study on HIV/AIDS stigma among health professionals found that most patients experienced stigma. Most patients felt that health professionals were the perpetrators for patients being stigmatised by communities because of their failure to maintain confidentiality of results that are HIV positive. Teenagers also indicated that they did not feel comfortable to attend contraceptive clinics with fear of having the information disclosed by health practitioners to members of the community.

Stigma is also experienced at the work place. In their study on stigma concerns and interventions, Esu-Williams et al (2004) found that workers who were living with

HIV/AIDS, experienced social isolation at the workplace as well as at the community. Stigmatisation hinders progress on interventions to mitigate the impact of HIV/AIDS. With fear of being stigmatised and discriminated against, it is cumbersome for individuals to access services aimed at addressing the pandemic for instance attending AIDS clinics which offer a holistic approach to HIV/AIDS.

Voluntary counselling and testing offers people an opportunity to be counselled and tested for HIV by health professionals. Many people who do not know their status indicated fear of being stigmatised as the main reason for not attending such clinics, hence remains not knowing their HIV status (Meidany et al 2003).

Various studies (Mboyi et al 2005; Meidany et al 2003) found that people diagnosed as HIV positive indicate that they prefer to disclose to close members of their families rather than people outside their families because of fear of being stigmatised by the community. The study also found that there was a high percentage of people living with the virus who felt comfortably to disclose to close family members rather than their spouses because of fear of being blamed by their spouses to have brought the virus.

Daigle et al (1999:267-268) indicates that Haitans felt stigmatised because of the media frenzy on the first cases of HIV. The presence of the home health-care nurse in the home of a patient can cause discomfort on the part of the family because of fear of being stigmatised and prejudiced against. “You may be designated the “AIDS nurse” in the community without your even knowing about it. If you are at a house, the assumption may be made that the patient inside the house has AIDS”, says Daigle et al (1999:268). The patients and the family are also faced with the fear of the further stigma associated with gay or prostitute stereotype.

2.9 Summary

It is apparent that hospitals and clinics would not be able to cope with the escalating number of AIDS patients because of the high number of people currently infected by the HIV. Gee et al (1988:280) state that community based care is seen to be the appropriate intervention. Despite its shortcomings it proves to be the best strategy if home health care workers can take the responsibility of educating families about AIDS and home caring.

Communities are developing robust approaches to mitigate the impact of the HIV/AIDS, hence the vast number of civil society organizations that are established. There are approximately 20 000 civil society organizations funded by the Department of Health to mitigate the impact of HIV/AIDS. Stigma and prejudice are seen to be hindering the progress of such interventions. Intensifying community education in relation to HIV/AIDS is recommended by many studies. Culture sensitivity is also seen to be important for the home based care programmes to function effectively.

Much is being said about the relationship between AIDS patients and caregivers as compared to volunteers and families of AIDS patients.

CHAPTER THREE

RESEARCH PROCEDURE

3.1 INTRODUCTION

This chapter focuses on the process the researcher embarked on in conducting the research. It outlines in detail the methodology followed and the sampling technique used in selecting the respondents. The chapter also highlights some demographic information about the site where the study was conducted.

The research seeks to explore salient issues underlying the perceptions and attitude of family members of AIDS ill patients towards community caregivers providing community/home based care services. Both the community caregiver and the immediate family were interviewed to establish comparative responses from both respondents' perspectives. In order to accomplish this, for each immediate family interviewed, its community caregiver was selected to participate in the study. Although the community caregiver was providing care and support to more than one AIDS ill patient in the community, the study narrowed the community caregiver's responses in relation to the family selected for the purpose of this study. This was emphasised to the community caregivers to restrict them from focusing on all their patients when answering the questionnaires. The sampling procedure used to obtain this sample will be discussed in section 3.4.

3.2 RESEARCH DESIGN

The research design chosen for this study is known as exploratory research design, because this is beginning research. The choice of this design was based on the fact that the area under study has not been well researched in the social work field. There are no sound social work theories regarding the perceptions and attitudes of family members of people living with HIV&AIDS towards community caregivers in the context of community/home based care programme. The critical question of the impact of community/home based care programme will be answered in this research design, and the answers will also modify the effective implementation of this programme in communities. According to Rubin & Babbie (1997:109) the exploratory design is conducive when the research seeks to test the feasibility of a method or wants to develop methods to be employed in a programme. The exploratory design is relevant for this study because its aim is to establish the requirements for effective implementation of community/home based care services to people infected and affected by HIV&AIDS.

Both quantitative and qualitative research methods will be used as outlined by Rubin & Babbie (1997:428-429). A qualitative method guided by phenomenological theory approaches was chosen to provide in-depth data about the family members' attitudes, knowledge, behaviors and experiences of community/home based care services.

Quantitative methods will compute results on how often the community caregivers involves the immediate in providing home caring and the number of families rejecting or accepting the community caregivers to enter their families. The level of satisfaction of both family members of people living with HIV&AIDS and community caregivers towards the community/home based care services will be assessed by using both qualitative and quantitative interviews.

3.3 RESEARCH INSTRUMENT

The research entails two themes. The first theme will focus on the community caregivers in order to determine their level of training, the type of services they provide to people living with HIV&AIDS and their families, as well as to determine the extent of the involvement of immediate families in providing care to their ill family members. The researcher will determine from the community caregivers' perspective their experience towards the community/home based care services and their working with families of people living with HIV&AIDS in providing care and support. The second theme will focus on the immediate families in order to establish how they perceive the community/home based care services and the extent of their involvement in working with the community caregivers. The researcher will administer two separate questionnaires for these two themes.

Two separate questionnaires were compiled and administered in order to obtain information regarding the two themes mentioned above and were based on the literature study. The questionnaire for the first theme (see Appendix A) obtained information from community caregivers regarding their level of training, type of services they provide, and the involvement of families in providing care to their ill family members (as mentioned in the previous paragraph). The questionnaire for the second theme (see Appendix B) obtained information from the families of people living with HIV&AIDS regarding how they perceive and accept the community caregivers and the services they are providing.

As suggested by Babbie (1998: 264-265) the researcher, for both questionnaires (the first theme that focused on community caregivers and the second theme that focused on the family members of people living with HIV/AIDS), conducted face-to-face interviews using standardized questionnaires comprising of both closed and open-ended questions. Open-ended questions were asked to enable the respondents to provide their own answers to the questions asked as outlined by Babbie (1998:148). Closed-ended questions were structured and allowed the respondents to select answers from among a list provided. As suggested by Babbie (1998:148), the closed-ended questions that required an endless list of responses were constructed in such a way that the response categories provided was exhaustive. In other words, the researcher provided an additional category and labeled it “Other, please specify”, to ensure that all expected possible responses are captured. Probes were used on closed questions for respondents to elaborate on certain responses to ensure the validity of the real meaning of the concept under study. Responses were recorded on the space provided in both questionnaires. In cases where respondents elaboration could not fit on the space provided in the questionnaire, notebooks were used to record additional notes. Questions were translated into a language understood by respondents. Three languages are used in the area where the study was conducted i.e. Xitsonga, Sepedi and Seswati. Interviews with families of people living with HIV&AIDS (that is the second theme) were conducted in their homes whereas interviews with community caregivers (that is the first theme) were conducted at the community/home based care site where they meet on weekly basis to submit reports of their daily home-visits to the project manager.

3.4 SAMPLING

The three community/home based care sites, namely Cunningmore, Hluvukani, and Maviljan, providing home-based care and support to people infected and affected by HIV & AIDS, had community caregivers ranging from twenty to forty per site. These numbers fluctuate owing to factors such as new recruitments, deaths, and securing better paying jobs elsewhere. ‘Cunningmore’ site catered for fourteen villages with one hundred and ninety-two people living with HIV & AIDS (included in this number were seventeen AIDS ill patients residing with extended family members). ‘Hluvukani’ site catered for eleven villages with two hundred and eighty- seven people living with HIV & AIDS (included in this number were twenty-nine AIDS ill patients residing with extended family members). ‘Maviljan’ site catered for five villages with one hundred and twenty five people living with HIV & AIDS (included in this number were thirteen AIDS ill patients residing with extended family members). These statistics were based on 2004 records from the three sites. Community/home based care sites have lists of people infected and affected by the pandemic and who are receiving services from the sites. For the researcher to be able to attain the objectives for the study, two samples were drawn from the community. The first sample focused on the immediate families of people living with HIV&AIDS while the second sample focused on community caregivers providing services to such families. Both samples will assist the researcher to understand both families and the community caregivers as far as their experience of the community/home based care services is concerned.

3.4.1 SAMPLE ONE: IMMEDIATE FAMILIES OF PEOPLE LIVING WITH HIV&AIDS

A sample of fifty families was selected from the sampling frame available at the three sites. This sample size was optimal for obtaining in-depth information from families to understand their perspective on working with community caregivers on the care and support they provide for their ill family members.

Probability sampling was used to select the fifty families to ensure that all families with terminally ill patients at home have an equal opportunity of being selected. Stratification approach in conjunction with systematic sampling was used to ensure representation of all fourteen villages and the three languages spoken in the Bushbuckridge Municipality (Rubin & Babbie 1997:237 & 255). Families were first grouped according to subsets (that is families were grouped according to villages and under each village they were grouped according to their spoken languages). Hluvukani had a population size of 10 families; with a sample size of 5 families, a sample interval of 2 was arrived at. Each family was allocated a number from 1 to 10. The first family was selected randomly to curb human bias. The number ‘1’ was selected from a random selection of numbers between 1 and 3. The family with an allocated number of 1 was selected and thereafter every second family from family 1 was selected i.e. 3, 5, 7 & 9. The criterion for inclusion that was used was that the family must have an AIDS ill family member at home who is being cared for by community caregivers, and the patient must have family members at home since family members are the unit of analysis instead of the patient.

The consent of family members to participate in the study was sought. All participants gave verbal consent.

The challenge experienced in this sample was a sudden death of a patient prior the interview. The researcher arrived at the families only to be informed that the patient died two days before the interview, and the family was still planning to inform the community caregiver. Replacement was made since the family felt that they could not participate in the study whilst in mourning. Table 3.1 below depicts the profile of the sample participated in the study:

Table 3.1: Sample characteristics of extended families

Number	Age	Gender	Number of people in household	Relationship to patient	Village	Ethnic group
1	85	Female	03	Grand Mother	Hluvukani	Xitsonga
2	43	Female	05	Sister	Matenteng	Sepedi
3	29	Female	02	Daughter	Hluvukani	Xitsonga
4	70	Male	06	Brother	Manyeleti	Xitsonga
5	33	Female	05	Sister	Ronaldsey	Sepedi
6	45	Female	04	Mother	Cunningmore	iSiswati
7	52	Female	05	Mother	Welverdiend	Xitsonga
8	30	Female	05	Aunt	Manyeleti	Xitsonga
9	50	Female	03	Mother	Cunningmore	Xitsonga

10	34	Male	08	Brother	Hluvukani	Xitsonga
11	32	Male	06	Brother	Hluvukani	Xitsonga
12	66	Female	08	Wife	Manyeleti	Xitsonga
13	48	Male	02	Son	Mphenyatsatsi	Sepedi
14	61	Female	05	Uncle	Welverdiend	Xitsonga
15	52	Female	04	Wife	Mphenyatsatsi	Sepedi
16	49	Male	03	Brother	Hluvukani	Xitsonga
17	69	Female	08	Sister	Matenteng	Sepedi
18	55	Female	05	Mother	Gottenburg	Sepedi
19	51	Female	12	Wife	Cunningmore	iSiswati
20	44	Female	06	Sister	Saville	Xitsonga
21	41	Female	08	Wife	Manyeleti	Xitsonga
22	57	Female	10	Sister	Saville	Xitsonga
23	76	Female	03	Mother	Gottenburg	Xitsonga

24	45	Female	09	Mother	Matenteng	Sepedi
25	46	Female	06	Sister	Matenteng	Sepedi
26	21	Female	03	Sister	ShangaanHill	Sepedi
27	48	Female	03	Mother	Gottenburg	Xitsonga
28	69	Female	04	Mother	Welverdiend	Sepedi
29	16	Female	08	Sister	ShangaanHill	Sepedi
30	33	Female	07	Aunt	Saville	Xitsonga
31	37	Female	05	Sister	Saville	Xitsonga
32	38	Female	09	Wife	Huttington	iSiswati
33	28	Male	19	Son	Belfast	iSiswati
34	64	Female	09	Mother	Belfsat	iSiswati
35	50	Female	14	Husband	ShangaanHill	Sepedi
36	41	Male	04	Brother	Belfast	iSiswati
37	44	Female	08	Sister	Culcutta	iSiswati

38	41	Female	04	Sister	Maviljan	Sepedi
39	42	Female	04	Mother	Huttington	iSiswati
40	59	Male	02	Husband	Maviljan	Sepedi
41	34	Female	07	Sister	Gottenburg	Xitsonga
42	27	Female	04	Mother	Ronaldsey	iSiswati
43	54	Female	06	Mother	Manyeleti	Sepedi
44	29	Female	06	Daughter	Culcutta	iSiswati
45	23	Female	04	Mother	Ronaldsey	iSiswati
46	48	Female	07	Husband	Huttington	iSiswati
47	20	Female	06	Daughter	Saville	Xitsonga
48	22	Female	03	Mother	Welverdiend	Xitsonga
49	45	Male	05	Husband	Culcutta	Xitsonga
50	52	Male	06	Uncle	Maviljan	Sepedi

3.4.2 SAMPLE TWO: COMMUNITY CAREGIVERS PROVIDING CARE AND SUPPORT TO PEOPLE LIVING WITH HIV&AIDS

A second sample of fifty community caregivers providing care and support to patients from the fifty families was selected in relation to the families selected for the study i.e. for each family that was selected, its community caregiver was subsequently selected.

The inclusion criteria was that the community caregiver must be attached to the community/home based care site and be monitored by the managers of that particular site. Each community caregiver was providing care and support to quite a number of people living with HIV/AIDS. This study focused only on patients whose family members were selected for the study. Table 3.2 depicts the sample characteristics of community caregivers participated in the study.

Table 3.2 Sample characteristics of community caregivers

Number	Age	Gender	Educational status (Grade)	Marital status	Ethnic group	Site
1	29	Male	Post matric	Married	Xitsonga	Hluvukani
2	29	Female	Post matric	Single	Xitsonga	Cunningmore
3	30	Female	Between grade 11-12	Single	Sepedi	Maviljan
4	30	Male	Post matric	Single	iSiswati	Cunningmore
5	30	Female	Post matric	Single	Xitsonga	Cunningmore
6	30	Female	Between grade 11-12	Married	Xitsonga	Cunningmore
7	31	Female	Between grade 11-12	Single	Xitsonga	Maviljan

8	31	Male	Between grade 11-12	Married	Xitsonga	Hluvukani
9	31	Male	Post matric	Single	Sepedi	Maviljan
10	31	Female	Post matric	Single	iSiswati	Cunningmore
11	31	Female	Post matric	Married	iSiswati	Cunningmore
12	33	Female	Post Matric	Single	Xitsonga	Cunningmore
13	33	Male	Between grade 11-12	Married	Xitsonga	Cunningmore
14	33	Male	Between grade 11-12	Married	Sepedi	Maviljan
15	33	Female	Post matric	Married	Sepedi	Maviljan
16	33	Female	Post matric	Single	Sepedi	Hluvukani
17	33	Female	Between grade 11-12	Single	Xitsonga	Cunningmore

18	33	Female	Between grade 11-12	Single	Xitsonga	Cunningmore
19	33	Female	Between grade 11-12	Single	Xitsonga	Hluvukani
20	34	Female	Post matric	Single	Xitsonga	Hluvukani
21	34	Female	Between grade 11-12	Single	iSiswati	Maviljan
22	35	Male	Post matric	Married	iSiswati	Cunningmore
23	35	Female	Between grade 11-12	Single	Xitsonga	Hluvukani
24	38	Female	Between grade 11-12	Single	Xitsonga	Hluvukani
25	38	Female	Between grade 11-12	Married	Xitsonga	Hluvukani
26	38	Female	Between grade 11-12	Married	Xitsonga	Hluvukani
27	39	Female	Between grade 11-12	Married	Xitsonga	Cunningmore

28	39	Female	Between grade 11-12	Single	iSiswati	Cunningmore
29	40	Female	Between grade 11-12	Single	Xitsonga	Hluvukani
30	40	Female	Between grade 3-7	Single	Sepedi	Maviljan
31	40	Female	Between grade 3-7	Single	Xitsonga	Hluvukani
32	40	Female	Between grade 8-10	Single	iSiswati	Cunningmore
33	40	Female	Between grade 11-12	Married	Xitsonga	Hluvukani
34	40	Female	Between grade 8-10	Married	Xitsonga	Hluvukani
35	41	Female	Between grade 8-10	Single	Sepedi	Maviljan
36	41	Female	Between grade 8-10	Single	Sepedi	Maviljan
37	41	Female	Between grade 8-10	Single	Xitsonga	Hluvukani
38	42	Female	Between grade 3-7	Single	Xitsonga	Hluvukani
39	42	Female	Between grade 8-10	Married	Xitsonga	Hluvukani

40	42	Female	Between grade 11-12	Married	Xitsonga	Hluvukani
41	46	Female	Between grade 8-10	Single	Xitsonga	Hluvukani
42	46	Female	Between grade 3-7	Married	Sepedi	Maviljan
43	46	Female	Between grade 3-7	Married	Xitsonga	Hluvukani
44	46	Female	Between grade 3-7	Married	Sepedi	Maviljan
45	47	Female	Between grade 3-7	Single	Xitsonga	Hluvukani
46	47	Female	Between grade 3-7	Married	Xitsonga	Hluvukani
47	50	Female	Between grade 3-7	Married	Sepedi	Maviljan
48	50	Female	Between grade 3-7	Married	Xitsonga	Hluvukani
49	51	Female	Between grade 3-7	Married	Xitsonga	Hluvukani
50	54	Female	Between grade 3-7	Married	Xitsonga	Hluvukani

3.5 DATA GATHERING

3.5.1 Sample of families

Face-to-face interviews were conducted to collect data from the families of the people living with HIV/AIDS as outlined by Babbie (1998:264-265). These interviews were conducted in the families’ homes. Questionnaire 2 (Appendix B) was used to gather the data from the families. The length of each interview varied from one hour to two hours. Various factors affected the length of the interviews i.e. interruptions by either family members or people passing by, some of the interviewees would request another family member to back their responses. At some families, interviews were conducted under the tree, as desired by the families. For each family selected for the study, one interview was conducted, bringing the number of interviews to fifty.

The interviews were arranged through the community/home based care sites. The community caregivers informed the families about the research during their visits to the families. The community caregivers explained to the families about the goal of the research i.e. to establish effective requirements for effective implementation of community/home based care services to people infected by HIV/AIDS. Although the community caregivers sought the families consent to participate in the study, the researcher first checked with the families whether they were aware of the research and whether they were still willing to participate in the study. All families selected for the study were willing to participate in the study, and they were aware of the research.

3.5.2 Sample of community caregivers

Interviews with the community caregivers were conducted at each community/home based care site, in a closed room provided by each site. The researcher sought permission from the project managers of the sites, to conduct the research. The researcher attended the community caregivers' meetings at each site to introduce the research and to seek consent from them. All Interviews were arranged to coincide with these meetings, to ensure that community caregivers' schedules of their roles towards families were not affected. Interviews commenced immediately after the community caregivers' meetings. Face-to-face interviews were conducted using questionnaire 1 (Appendix A). For each community caregiver participated in the study, one interview was conducted. The length of the interviews varied from forty-five minutes to ninety minutes. All community caregivers interviewed, were willing to participate in the study.

3.6 DATA ANALYSIS

Questionnaires were used to collect data from the samples. The questionnaires had both closed and open-ended questions. Each question had a numerical code for each appropriate response guided by both nominal and ordinal measurement levels (Rubin & Babbie 1997:157-158). With regard to nominal measurement, a variable like *training provider* with the following attributes: *1.Government, 2.University, and 3. Non-Governmental Organization;* implied that the number assigned to each of the attribute does not reflect that the attribute with a higher number carries more weight than the one with a low number. In other words the numerical code referred only to the name of the training provider. However, with ordinal measurement used, the rank order of the attributes indicated the more or less of the variable. For instance, the variable like *qualification* with the following attributes: *1. Below grade three, 2.Grade three to grade seven. 3. Grade eight to grade ten, 4. Grade eleven to grade twelve, and 5. Post matric;* implied that code four represented a higher qualification than code 3, 2 and 1 but rated less than code 5. But this does not mean that code four has rated four times ‘better or higher” than code 1 (Rubin & Babbie 1997:158).

The numerical codes for each response made it easier for the researcher to employ the edge-coding technique when entering data. Open-ended questions, from both the questionnaire and the notebook, were coded in terms of the variable under study i.e. whether the aspect of the variable was mentioned (Rubin & Babbie 1997:397-399). For instance, with the variable *stigmatization by community*, the responses were coded in terms of whether the participant’s response indicates that the community is stigmatizing the family or not. The responses were thus quantified for analysis.

Face-to-face interview approach was used when collecting data. This eliminated the possibility of having any missing data.

3.7 STUDY SITE

Limpopo province forms part of the border separating the Republic of South Africa from its neighbouring states Zimbabwe and Mozambique. According to Census 2001 Statistics, the province had a population of 5 273 642, of which 5 128 616 were Africans. Administratively, Limpopo Province is divided into six Districts, in which Bohlabela is one of them. According to Census 2001 Statistics, Bohlabela District had a population of 597 735 in which 592 783 were Africans. The District is divided into two Municipalities i.e. Maruleng Municipality and Bushbuckridge Municipality. The study was conducted in the Bushbuckridge Municipality. According to Census 2001 Statistics, Bushbuckridge Municipality had a population of 499 697 of which 498 452 were Africans. It had three community/home based care sites that had been in existence since 1999, 2000 and 2001, respectively. Maruleng Municipality did not have any community/home based care programs during the time of this research. They have been included on the rollout plan of the Department of Health for the next financial year 2005/2006 to be funded for a community/home based care site.

According to the 2003 Annual HIV/Syphilis Seroprevalence survey (Epidemiology Section, Limpopo Department of Health and Welfare), the HIV & AIDS prevalence was 20.2% of the total population of the Bohlabela district. The district was in second position when compared with the Province’s six districts according to this survey. Despite efforts of awareness campaigns in the district, the rate of HIV prevalence in the district is escalating according to this survey. In 1999 the prevalence was 11% and in 2000 it was 16%.

There are many game lodges in the District including the Kruger National Park and this attracts many tourists. There are also many farms around the District. Most of the people from the Bushbuckridge are working in these farms and game lodges. HIV&AIDS awareness campaigns do not reach them because they are conducted when they are at work and their employers are adamant to allow them to attend such campaigns because they interfere with the production. This makes them to be more vulnerable to HIV infections.

Three languages are spoken by most of the inhabitants i.e. Xitsonga, Sepedi and siSwati. The following table depicts the breakdown of languages in the Bushbuckridge Municipality (Census 2001 Statistics).

Table 3.3: Languages spoken in the Bushbuckridge municipality

Language	**Number of people**
Afrikaans	694
English	542
IsiNdebele	159
IsiXhosa	395
IsiZulu	16 806
Sepedi	132 439
Sesotho	22 019
Setswana	716
SiSwati	38 090
Tshivenda	380
Xitsonga	287 088
Total	499 328

According to Census 2001 Statistics, the villages of this Municipality are rural. About 65 023 of the population were unemployed while 164 417 were not economically active (that is the people are not engaged in any kind of income generating activities). Those with employment, some are working in Government offices, some at shopping complexes, while most are working on the farms and game lodges. Although the large number of game lodges and farms elicit economic growth, it is seen as bringing negative influence to the community because the prevalence rates for HIV infection was much higher amongst people working on the farms and game lodges. However, the contributing factor could be that awareness campaigns are being carried out at communities when the farm laborers and game lodges are in operation, thus excluding them from accessing information about HIV/AIDS. Until the late nineties, Managers of these farms and game lodges did not allow Health and Welfare officers to conduct awareness campaigns because they felt that it hinders the operation of their business.

The research project focused on three community/home based care sites i.e. Cunningmore, Hluvukani and Maviljan. Two of the sites i.e. Hluvukani and Cunningmore are bordering the Kruger National Park, and have most of its inhabitants working at the Park. Maviljan is approximately two kilometers towards Mapulaneng hospital. Cunningmore is approximately ten kilometers from Matikwana hospital while Hluvukani is approximately thirty-two kilometers from their nearest hospital Tintswalo.

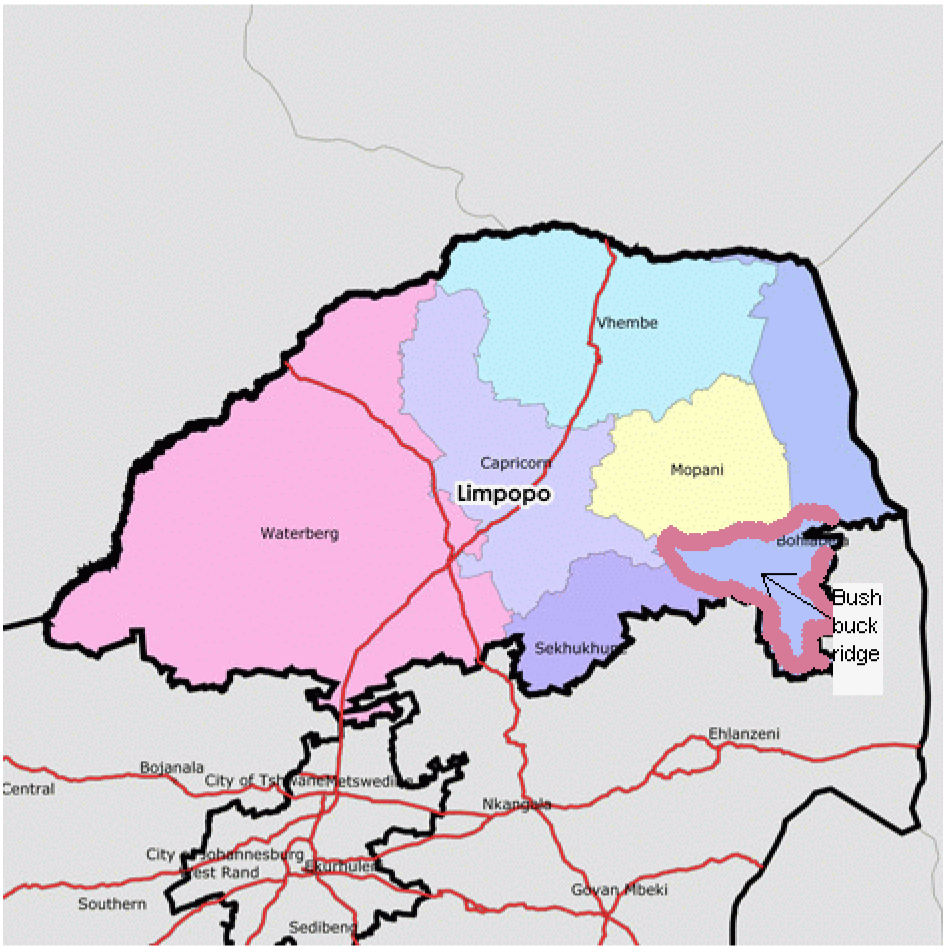
The map below shows the location of Bushbuckridge Municipality within the map of the Republic of South Africa, where the study was conducted. Bushbuckridge is shaded in blue in Limpopo province, for easy reference.

Map 3.1: Location of Bushbuckridge within South Africa

Source: www.places.co.za

The following is the map of Limpopo province depicting the location of Bushbuckridge under Bohlabela district. Bushbuckridge municipality is bordered with pink with an arrow for easy reference.

Map 3.2: Location of Bushbuckridge at Bohlabela district in Limpopo Province



Source: www.demarcationboard.org.za

CHAPTER FOUR

RESEARCH FINDINGS

4.1 INTRODUCTION

This chapter outlines the findings of the research. The content is captured under four themes that emerged from the two questionnaire i.e. the level of training of community caregivers; services rendered to families with people living with HIV&AIDS; the involvement of family members in the care and support of their ill family members; and the attitudes and the level of satisfaction of family members of people living with HIV&AIDS towards community caregivers.

Results that emerged from the two separate questionnaires that addressed reciprocal issues are presented in an integrated manner in order to compare such results from the family members and community caregivers.

The findings are depicted in graphic form and tables. These are then discussed in detail.

4.2 COMMUNITY CAREGIVERS PROVIDING CARE AND SUPPORT.

4.2.1 Profile data of community caregivers

There were fifty community caregivers providing care and support to families with persons living with HIV&AIDS, attached to the three community/home based care sites (Cunnungmore, Hluvukani and Maviljan), who participated in the study.

The data of the community caregivers indicated the age range from twenty-nine years to fifty-four years with a mode of forty-six years and a mean = 37.98 years. At least 34 (68%) of the community caregivers participated in the study aged between 29years and forty years. The study found that 43 (86%) of the community caregivers were females. The results are confirmed by Richardson (1989:130) when he defined caring as an activity that is always carried out by women, because as a wife and a mother, the woman is expected to care for her children and family. In terms of their marital status, 27 (54%) of the participants were single. There were 34 (68%) community caregivers who indicated that they had been community caregivers attached to a community/home based care sites for at least one year or more than one year. At least 31 (62%) of the community caregivers indicated to have a formal qualification of between grade 11 and post grade 12. This is presented in the following table 4.1

Table 4.1: Educational level of community caregivers

Qualification	**n**	**%**
Grade 3 to 7	12	24
Grade 8 to 10	7	14
Grade 11 to 12	19	38
Post matric	12	24
Total	50	100

4.2.2 The level of training of community caregivers

4.2.2.1 Community caregiving training

The following table depicts the number of community caregivers who either received or did not receive training as caregivers:

Table 4:2 Community caregivers trained on caregiving

Community Caregivers received caregiving training	**n**	**%**
	36	72
Community caregivers did not received training	14	28
Total	50	100

The study found that (36) 72% of the community caregivers have received training on provision of care and support to people living with HIV & AIDS. The training course included the following: home-based care, lay counseling for people living with HIV & AIDS, child care, sexually transmitted infections and direct observation treatment for TB patients. All 36 trained community caregivers reported that the training was relevant and enhancing on their rendering of services to people living with the pandemic. In terms of HIV & AIDS they had gained vital knowledge on modes of transmission, prevention, opportunistic infections, treatment, care and support of HIV & AIDS patients and legal aspects.

4.2.2.2 Length of the training

Table 4.3: Duration of training received by community caregivers

Length of Training	**n**	**%**
Two weeks	8	22
36 days	28	78
Total	36	100

The information presented in the above table 4.3 reflects only the number of community caregivers who were trained on caregiving, as depicted on table 4.2. From table 4.2, it was found that 36 community caregivers have received training on caregiving. The above table 4.3 outlines the duration of the training these 36 community caregivers received.

At least 28 (78%) of the trained community caregivers have completed thirty-six days of the stipulated fifty-nine days training course. The National Department of

Health has developed a training manual for home-based care services, which is structured over fifty-nine days of training sessions i.e. Learner handbook for the training of home/community based caregivers: Department of Health 2001. All community caregivers need to be trained on this manual because Health and Welfare SETA has accredited it. Only community caregivers who complete the fifty-nine days training sessions successfully, are given certificates.

Although 14 (28%) of the community caregivers (as depicted in table 4.2) reported to have not received training on care and support for people living with HIV & AIDS, they reported that they had attended at least some presentation on HIV & AIDS during community awareness campaigns e.g. World AIDS Day or Condom week. They also indicated that the project managers took them through on how to care for people infected by the pandemic during a one-day orientation program. However, they felt that there is a need for them to be properly trained on how to provide care and support to people affected by the pandemic. They also mentioned that training should be done before they could start visiting families. Reason given for them not having been trained yet was that the community/home based care site did not have enough funds for the training, but plans have been made for them to be trained in their next financial year.

There were three community caregivers who reported that they were trained on direct observation treatment for patients with Tuberculosis before they joined the community/home based care site. Although there are similarities on how to care for patients at home, they all felt that they also need to be trained on lay counseling.

When asked on how lack of training affects their provision of services, they all reported that not knowing how to provide lay counseling to terminally ill patients and their families frustrated them. They were not better equipped to give patients qualitative information and to answer questions pertaining to HIV & AIDS and providing proper referrals to resource agencies or other departments

4.2.2.3 Type of training received

The following table indicates the type of training received by the community caregivers. The information is based on the 36 number of community caregivers that received training.

Table 4.4: Type of training received by community caregivers

Type of training	**n**	**%**
Home based care	36	100
Lay counselling	36	100
Child & Youth care	36	100
HIV & AIDS	36	100
TB/DOTS	7	19

The information presented in table 4.4 is related to table 4.2, i.e. community caregivers who were trained on caregiving. From the 36 community caregivers who indicated that they received training on the provision of care and support to people living with HIV&AIDS, all 36 (100%) community caregivers indicated that the type of training received was home based care, lay counseling, child and youth care, and HIV&AIDS. It is apparent from the information presented above that each community caregiver was trained on more than one topic.

4.2.2.4 Stipend

Stipend means remuneration that can be in the form of money. The Department of Health and Welfare do not fund the community/home based care sites for stipend. However, recommendations to the Department have been made by the programme managers to consider the funding of stipend by increasing the funding that is currently disbursed to the community/home based care sites. The National Department of Health and Social Development are currently exploring the issue of stipends. All 50 (100%) community caregivers participated in the study reported that they do not receive monthly stipend for the services they are providing. They were all aware when they were recruited that they will not be remunerated. The funding which the community/home based care sites received from the Department of Health and Welfare is meant for capacity building, community mobilization, transport, and office equipments e.g. stationery. However, most felt that because they are assisting the Department of Health, by caring for patients at home rather than having nurses to care for these patients at hospitals, the Department of Health and Welfare should consider remunerating them. Many of the participants reflected on how they put their lives at risk by caring for people infected by the deadly virus and yet they are not paid.

The study indicated that 34 (68%) of the participants had been working as community caregivers attached to the community/home based care sites for more than a year, (the maximum length being over six years), but they had received a stipend of only R500 for three months from Department of Health and Welfare (Limpopo province) on January 2004. Some of the participants commented that the lack of stipend contributes to community/home based care sites loosing trained community caregivers for better paying jobs elsewhere. This leaves the community/home based care sites with new unskilled recruits. Most participants alluded that even if they can be compensated with food parcels they would appreciate it.

It is apparent from the findings that most of the community caregivers had a formal education; and they were trained on care and support to people living with HIV&AIDS. It was noted that the training status was impacting positively on their care and support activities towards people living with the pandemic. However, it was noted that the lack of incentives to community caregivers undermined the provision of community/home based care services. Although this is not the purpose of the research, the researcher is trying to determine whether the level of training could have an effect on how families perceive community/home based care; for future research as well.

4.3 SERVICES RENDERED TO PEOPLE LIVING WITH THE HIV & AIDS AND THEIR FAMILIES

As stipulated in the Learner Handbook for the Training of Home/Community Based Caregivers (2001:20-21), the roles of community caregivers include provision of services to orphans and vulnerable children infected and affected by the pandemic; and provision of services to people living with the pandemic. In terms of orphans and vulnerable children, they provide the following services:

- Identification of children who are in need of care and protection.
- Referrals to social services for application for social grants and other relevant interventions.
- Provision of food parcels, clothing, shelter, alternative care (preferably in the community for example foster care) and social relief in partnership with the Welfare Department for poor clients.
- Child protection from abuse and neglect.
- Facilitate support groups for children in distress.

In terms of services towards AIDS ill patients, the following are the roles of community caregivers as outlined in the training manual:

- Physical care of the terminally ill person which includes bed bath, wound care, pressure sores, and changing diapers and bed linen.
- Nutritional care, which includes preparation of proper meals depending on the medical condition of the patient and assist in feeding the patient.
- Physical environment including household activities, equipment needed to facilitate caring, drawing up of wills, memory boxes and referrals.

- Emotional support, which includes lay counseling for the dying person and the affected family, bereavement support, and referrals.
- Health education i.e. educating the family on hygiene, basic caring skills, nutritional advice and infection control.
- Assistance with social grants e.g. disability grants.
- Community mobilization.

The following principles and values of care and support are also outlined in the training manual:

- Respect
- Confidentiality
- Equity
- Accessibility and availability
- Accountability
- Efficiency and effectiveness
- Sustainability

The training of community caregivers is not limited to be provided by health professionals only. The community/home based care sites can outsource other trainers. However, the service providers should have a SETA or South African Qualification Authority accreditation to be able to provide trainees with certificates.

4.3.1 Recruitment as community caregivers

Community caregivers are the core to service delivery of the community/home based care programme. The way in which these community caregivers are selected, trained, utilized and given on-going support will determine whether the programme succeeds or fails. According to the Guidelines for Establishing Home/Community-Based Care & Support Programmes (2003:27), in selecting volunteer caregivers, the recommended person should be trustworthy, have a good social standing, respected, easy to communicate with, and non-judgmental. Because community/home based care sites' funds are not sufficient, the sites prefer to place community caregivers at their respective communities. In this way, community caregivers do not travel long distances to visit the families.

The table below indicates how the community caregivers were recruited to join the community/home based care sites:

Table 4.5: Recruitment systems

Type of recruitment	n	%
Recommended by community leader	7	14
Recruited through the community radio	2	4
Word of mouth	34	68
Clinic	7	14
Total	50	100

The information presented above in table 4.5 indicates that the ‘word of mouth’ method is a prominent way of recruiting the community caregivers. According to the community caregivers, this method is effective because some people do not have access to the media. School going children always deliver messages to their parents whenever an announcement is made at school. Messages to request volunteers were sent to churches, schools, and women’s groups. Individuals who were interested were requested to visit the community/home based care sites to register as volunteers. Community caregivers indicated that the project managers and the members of the projects’ executive members interviewed them before they joined the sites.

4.3.2 Duration of providing care and support by community caregivers

The table below indicates the duration that the community caregivers have been providing care and support to people living with HIV&AIDS. The information seeks to establish the stability of community caregivers within the community/home based care sites. It is important for people living with HIV/AIDS and their families to build rapport with a community caregiver rather than having different community caregivers visiting their families. This helps families to know and understand their community caregivers.

Table 4.6: Duration of providing care and support

Duration	**n**	**%**
Less than six months	5	10
Six to twelve months	11	22
One year to two years	9	18
Two years to three years	16	32
Three years and above	9	18
Total	50	100

From the information presented above, it is noted that a large number of community caregivers have been with the community/based care programme for more than two years as community caregivers. Most of the community caregivers who were less than two years had a matric or post matric educational status. They were seeking employment elsewhere. It is evident that community caregivers with matric and post matric status were not stable in the programme because they were able to get employment that will pay them salaries.

4.3.3 Breakdown of patients receiving care and support from community Caregivers

The following table indicates the breakdown of patients according to gender, who are being cared for by the 50 community caregivers participated in the study. The table presents all patients that the community caregivers are providing care and support. The patients from the 50 families under study are also included in this table. This table serves to depict the workload of the community caregivers broadly:

Table 4.7: Gender of patients

Adult males	Adult females	Boys	Girls	TOTAL
106	161	33	59	**359**

The table above depicts an average of 7.2 number of patients per community caregiver. It is apparent that most of the patients that are being cared for by the community caregivers are adult females. The community caregivers indicated that most of the AIDS ill children are often cared for by their mothers. However, they do care for sick children whose mothers are either bedridden or deceased. Most of their child patients come from child/youth headed households. In terms of the children from child / youth headed households, the patient is usually the smallest child. When the child becomes very sick, the elderly child had to absent him/her from school in order to be with the child. This is confirmed by most studies done on the impact of HIV&AIDS on the community. Dossier (1992:45) & Modly (1997:173-176) indicated that poor socio-economic standards undermine traditional practices of many households to take these orphans into their homes, thus leaving many children to head families.

4.3.4 Characteristics of patients

The table below indicates certain characteristics of the patients from the 50 families studied. Studies (Whiteside & Sunter 2000:32) indicate that the pandemic strikes adults who are mostly the backbone of the country’s labour force and are providing for their families. The pandemic also threatens the extremely important norms and values of families. For instance, the elderly and the children are faced with the role of caring for the sick. The table below seeks to establish the kind of patients who are infected by the pandemic. Each characteristic depicts the number of patients out of the 50 families studied.

Table 4.8: Characteristics of patients

Characteristics of patients	**Number of patients out of the 50 families**	**%**
Patients who head families	35	70
Patients who are breadwinners	34	68
Patients who have children under the age of 18 as their primary caregivers	3	6
Patients who have adults as their primary caregivers	47	94
Patients who have elderly (aged) people as their primary caregivers	5	10

The information presented above indicates that at least 35 (70%) of the patients receiving care and support from the community caregivers were reported to be heads of the families and 34 (68%) were breadwinners. The study also indicated that 5 (10%) of the patients had elderly people and 3 (6%) had minor children providing care and support for them during the community caregiver’s absence. The study found that there were many adults infected by HIV that were breadwinners and heading families. This confirms the findings of the research done by Whiteside &

Sunter (2000: 32) as alluded above, that the pandemic strikes adults who are mostly the backbone of the country's labour force. The study also found that many of the patients were cared for by adults as compared to children. There were few patients that had children or elderly persons as primary caregivers.

4.3.5 Number of visits per family

The table below depicts the number of visits done by community caregivers for each patient per week. The frequency presented in this table is focusing only on the patients from the 50 families selected for this study:

Table 4.9: Frequency of visits

Number of visits	n	%
Once per week	17	34
Twice per week	26	52
Thrice per week	5	10
Bi-weekly (once in 2 weeks)	2	4
Total	50	100

From the study, 26 (52%) of the community caregivers visit the same patient twice per week. They indicated that the number of visits is determined by the medical condition of the patient and the willingness of family members to provide care to the patient during the absence of the community caregiver. Many community caregivers pointed out that they spent two hours or more providing services per family visit. However, they alluded that the length of each visit depends on whether the patient’s family members assisted them during the provision of care and support especially during the bed bathing because it requires a lot of things i.e. putting on a fire to warm the water, undressing the terminally ill patient and dressing him/her after the bath, brushing the patient’s teeth, nail and hair care, dressing wounds if any, and remaking the patient’s bed. Community caregivers indicated that they visit patients that have children and the elderly persons as primary caregivers more often in order to provide support to these primary caregivers.

4.3.6 Services provided by community caregivers

(a) Community caregivers’ perspectives

Community caregivers reported to be providing the following services to people living with HIV&AIDS:

- Lay counselling
- Health education
- Physical care
- Nutritional care
- Physical environment
- Distribution of food parcels
- Referrals to relevant resources

According to the roles of community caregivers as stipulated in the Learner Handbook for the Training of Home/Community Based Caregivers (2001:20-21), it is apparent that the community caregivers were providing services to people living with HIV&AIDS as expected and even more, in the sense that the community caregivers were also distributing food parcels to needy families as well as monitoring adherence of patience to their medication.

(b) Immediate families' perspectives

Family members were asked to outline the type of services which community caregivers provide to the patients. The information presented in the table below is linked to the information presented above under paragraph (a) i.e. community caregivers' perspectives.

The following table indicates the type of services provided by the community caregivers. Multiple responses were of course self evident in a caring situation:

Table 4.10: Services rendered by community caregivers

Type of services	**n**	**%**
Bathing	34	68
Feeding	34	68
Lay counselling	50	100
Family Support	50	100
Provision of food parcels	50	100
Monitor patient's intake of medicine	50	100
Cleaning the room of the patient	50	100

Thirty four (68%) families reported that the community caregivers were bathing and feeding the patients during their visits, these were patients who were very sick and were unable to take care of themselves. Some of the people living with HIV&AIDS were however not bedridden. Family members indicated that community caregivers were not providing services such as bathing or feeding to these patients because they were not bedridden.

Table 4.9 above, shows that at least 26 (52%) patients were visited by their community caregivers at least twice per week. Five (10%) were visited at least thrice per week. The frequency of the visits by the community caregivers, and the type of services which they provide differ for each patient. The medical condition of the patients is found to be a determinant of the frequency of visits and the type of services provided. For instance, table 4.10 shows that only 34 (68%) of the patients were bathed and fed by community caregivers during their visits because they were very sick to be able to bath and feed themselves. The other 16 (32%) were able to bath and feed themselves because they were not as sick as the other 34 (68%).

4.3.7 Home based care kits

According to the Learner Handbook for the Training of Home/Community Based Caregivers (2001), the kit is a bag with hundred medium examination gloves, gauze bandages, hundred gauze swabs 100mm x 100mm, linen savers, plastic apron, and oral rehydration. Each community/home based care site should ensure that each community caregiver has a home based care kit which he/she carries when visiting the families. Especially when the patients are bed-ridden and have wounds. The kits have examination gloves that can be used by the caregivers to protect themselves from touching the wounds of their patients with their bare hands. The project managers keep an inventory of the contents in each kit. They inform the local clinics regularly to replace supplies that have been used. The information presented under this sub-heading provides holistic picture within the context of care and support provided by the community caregivers.

The following table indicates the number of community caregivers who have home based care kits:

Table 4.11: Availability of home based care kits

Home based care kits	**n**	**%**
Yes	21	42
No	29	58
Total	50	100

There were 29 (58%) respondents who indicated that they did not have home-based care kits. These community caregivers indicated that the local clinics provide them with examination gloves to use when providing physical care to patients who are bed-ridden, to protect them from getting infections. They indicated that it is cumbersome for them to visit families without the kits. Especially when the patients have wounds that need to be dressed. The community caregivers give advice to the families members to take the patients to clinics for proper medical examination.

Table 4.12: The suppliers of home based care kits

The following table illustrates how the 21 community caregivers got their home based care kits:

Supplier	**n**	**%**
Provincial Department of Health and Welfare	9	43
National Department of Health	5	24
Community/home based care site	7	33
Total	21	100

It is apparent from the information presented above that the Department of Health is the fundamental supplier of community/home based care sites with home based care kits. At least 14 (67%) of those with home-based care kits received them from the provincial Department of Health and Welfare and the national Department of Health. These kits are distributed to the community caregivers by the district HIV&AIDS coordinators. However, 7 (33%) reported that they received the kits from the community/home based care sites. These kits are donated by outside sources.

Table 4.13: Refilling of the home based care kits

The following table indicates whether home based care kits are refilled regularly by the local clinics. The local clinics replace items that are depleted to enable the community caregivers to provide effective services to people living with HIV/AIDS.

Whether kits are refilled regularly	**n**	**%**
Yes	9	43
No	12	57
Total	21	100

From the 21 (42%) community caregivers who reported to have home-based care kits (see table 4.11 above), 12 (57%) pointed out that these kits are not refilled regularly by the local clinics. Reason given for their kits not refilled regularly was shortage of medical supplies at clinics. They indicated that many a times when they took their patients to the clinics, they were told that there was no medication. This did not happen to their patients only, but also to the community in general. The health professionals told them that the shortage of medication is a common problem in the entire district. While community caregivers wait for their kits to be refilled, some family members buy wound-dressers from the chemists. Some families, including those who do not have money to buy from the chemist, use indigenous ways of dressing the wounds. For instance, they use barks of certain trees that are specially prepared to make a wound-dresser.

4.3.8 Debriefing Services

Caring for dying people can have negative effects to the community caregivers. For instance, this can raise issues related to the community caregivers' own death experiences. Community caregivers become deeply involved in the lives and well being of others. They are regularly exposed to human grief and the inability of others to cope adequately with their daily functions. For optimum care to take place, support services that include monthly debriefing sessions by expend counselors, should be provided to community caregivers. Services of a pastor or a social worker can be sought to offer debriefing services to the community caregivers. Both group and individual counseling sessions should be made available to community caregivers (Family Life Support Centre: 37).

The following table indicates whether community caregivers receive debriefing services:

Table 4.14: Community caregivers that receive debriefing services

Whether community caregivers receive debriefing services	**n**	**%**
Yes	50	100
Total	50	100

The following table indicates the provider of the debriefing services:

Table 4.15: The provider of debriefing services

Provider of debriefing services	**n**	**%**
Project manager	34	68
Social worker	7	14
Nurse	9	18
Total	50	100

Table 4.14 above indicates that all community caregivers receive debriefing services offered at the community/home based care sites. Table 4.15 shows that at least 34 (68%) of the community caregivers indicated that the project manager of the community based care site conducted the debriefing sessions during the community caregivers' weekly meetings at the organisation. The project manager allowed them ample opportunity to talk about the frustrations and problems experienced during the week when they visited the families. They felt that the debriefing services they received helped them to offload the emotional burden they carry especially when their patients died. Dying patients and death of a patient were outlined as demotivating factors towards their service rendering as one community caregiver said: (translated from Xitsonga)

"I visited my patient one day and found her gasping. It took away my appetite when I arrived home. I went straight into my bedroom and just stared at the ceiling. I was afraid to visit the next day thinking that she might be dead. I first checked with the neighbors whether they heard a death pronouncement by the family in order to enter the house prepared. And of course she died during the night."

The information presented under table 4.15 above shows that only 7 (14%) community caregivers are receiving debriefing services from the social worker, and 9 (18%) from a professional nurse, who is working on the HIV&AIDS unit at the clinic. It is evident that most community caregivers are not receiving debriefing services from professionals because the project managers are not professionals.

4.3.9 Satisfaction as community caregivers

For a community/home based care programme to be effective, it is important for the community caregivers to be satisfied with their roles.

The table below indicates whether community caregivers are satisfied as a community caregiver:

Table 4.16: Level of satisfaction for community caregivers

Satisfaction	**n**	**%**
Yes	45	90
No	5	10
Total	50	100

The table shows that 90% of the community caregivers indicated that they were satisfied with their roles as community caregivers. The following were alluded as giving them satisfaction:

- Helping sick people who are unable to help themselves and watch them getting better, especially after bathing and feeding the patients and saw them clean and satisfied.

- When families' vegetable gardens provided the patients with fresh vegetables. Especially because they were advised by the community caregiver to start such gardens at home.
- Providing lay counseling and support to patients and their families, and seeing patients talking freely about their problems with them because of the trust that patients have developed towards them.
- When patients takes into cognizance the advices of the community caregiver and act upon them e.g. taking their pills.

Although a large number of community caregivers indicated that they were satisfied with their roles as caregivers, they still experienced things that discourage them from time to time. They made some recommendations that could make the community/home based care programme to be successful (see next sub-heading 4.3.10).

The following were highlighted by respondents as demotivating factors to the rendering of services to people living with HIV&AIDS and their families:

- Lack of stipend.
- Lack and irregular refilling of home-based care kits, which put their lives at high risk of being infected by the HI virus.
- Patients lacking food as a result their immune system is suppressed to fight opportunistic infections.
- When relatives were not willing to assist in the process of care and support of their ill family members.
- Lack of treatment for people living with HIV & AIDS.
- Being labelled by communities as "people who care for AIDS patients".

- Families who do not allow them to enter patients’ rooms.
- When families choose to refer their ill family members to traditional practitioners rather than hospitals.

4.3.10 Community caregivers’ recommendations for the community/home based care programme to function optimally

Community caregivers gave the following recommendations for the community/home based care service to be operational workable:

- Food parcels for people living with HIV & AIDS who are poor should be provided on a monthly basis. Proper nutrition is essential to help improve the immune system of people infected with HIV.
- Provision of home/based care kits and regular filling of these kits by local clinics is essential to ensure that community caregivers are able to care for patients’ sores and wounds in a proper and safe way.
- Provision of Anti-Retroviral drugs for AIDS ill patients by the local clinics will help patients to become better.
- Training of new recruits i.e. new community caregivers is essential to equip them with knowledge and skills to be able to provide proper care to people living with HIV/AIDS and their families.
- Provision of stipends by the Department of Health and Welfare will help to retain community caregivers within the community/home based care sites.
- Provision of umbrellas for hot and rainy weather for community caregivers will help to improve the working conditions of community caregivers.

4.4 INVOLVEMENT OF EXTENDED FAMILIES OF PEOPLE LIVING WITH HIV & AIDS PANDEMIC TOWARDS THE CARE AND SUPPORT OF THEIR ILL FAMILY MEMBERS

The fifty community caregivers participated in the first two sections were also participants in this section, in order to understand in their perspective the involvement of family members of people living with HIV & AIDS towards the provision of care and support to their ill members. Information from the fifty families is also presented in this section to provide a comprehensive picture and to compare the results. The purpose of community/home based care programme is to impart the skills of caring for people living with HIV&AIDS to family members. Community/home based care programme does not disempower family members from care towards their ill family members. It serves to assist and support families to alleviate the burden of caring for a bed-ridden patient alone. The involvement of family members during the care and support to patients with HIV&AIDS ensures that family members will continue to care for their ill family members in a safe and caring environment.

4.4.1 Care of patients by family members based on the perspectives of community caregivers

Patients who are in the last stages of HIV are bed-ridden and are not able to bath or feed themselves. It is important that family members should continue providing care to their ill patients when the community caregivers are not visiting the patients for that particular day.

The following table indicates the number of community caregivers who found their patients bathed by family members during their visits to the families:

Table 4.17: Patients bathed by family members

Whether patients were bathed	**n**	**%**
Yes	43	86
No	7	14
Total	50	100

The following table indicates the number of community caregivers who found their patients fed by family members during their visits to the families:

Table 4.18: Patients fed by family members

Whether patients were fed	**n**	**%**
Yes	43	86
No	7	14
Total	50	100

The following table indicates the number of community caregivers who found their patients' rooms cleaned by family members during their visits to the families:

Table 4.19: Patients' room cleaned by family members

Whether patient's room was cleaned?	**n**	**%**
Yes	43	86
No	7	14
Total	50	100

Tables 4.17, 4.18 and 4.19 show that from the 50 community caregivers participated in the study, 43 (86%) of them reported to have found patients bathed, fed and their rooms cleaned by family members. Some community caregivers reported that it depends on the time they visit the family. When the visits are done very early in the morning i.e. before 9H00, they sometimes find the patients not bathed. Caregivers start their family visits from 8H00. Community caregivers who indicated that they found the patients not bathed, fed, and their rooms not cleaned, explained that the families knew that the community caregiver was coming that particular day. They wanted the community caregiver to do what he/she came to do i.e. to provide care that includes the bathing and feeding the patient. According to the community caregivers these family members bath, feed, and clean the patient's rooms when they are not expecting the community caregivers to visit the patient for that particular day. It is evident from the information presented in this table that all family members do provide care and support to their ill family members when the community caregivers are not visiting the patients.

4.4.2 Family members providing care and support to their ill family members

According to Dossier 1992:45 & Modly 1997:173-176, the role of caring for the sick is now shifting to children and the elderly because of the HIV&AIDS pandemic. The information presented in table 4.8 above also indicates that children and the elderly are providing care to their ill patients. This confirms what these two authors mentioned above have said. It is important for the community/home based care programme to be aware of the patients' primary caregivers. This will enable the programme to target its support services effectively. The following table 4.20 illustrate the patients' main primary caregivers when the community caregivers are not visiting the patients.

Family members mostly indicated as providing care and support to their ill family members from the findings were:

Table 4.20: Relationship of the family member providing care and support to the patient

Relationship to Patient	**n**	**%**
Patient's mother	26	52
Patient's grandmother	5	10
Patient's child	3	6
Patient's wife	7	14
Patient's sister	6	12
Patient's husband	1	2
Patient's brother	2	4
Total	50	100

One of the respondents reported that the primary carer was a husband who provided care to his ill wife. Only 10% of the patients had elderly people and 6% children as their primary carers at home. According to community caregivers, families provided care towards their ill families because it was altruistic. The information presented above indicates that there were children and the elderly that are primary caregivers to the patients. Families with children as primary caregivers had elder family members who were working during week days. These elder family members were able to care for their ill family members on weekends and when they were on leave. Community caregivers indicated that they visit families with children as primary caregivers at least twice per week. The data also concurs with Richardson (1989: 130) when he said that caring is often carried out by women. The table illustrates that 47 (94%) of the primary caregivers for the patients were women.

4.4.3 Participation of family members in caring for the sick patient with the community caregivers

Community/home based care programmes aim at imparting skills on how to care for people living with HIV&AIDS to family members. Family members should participate in the provision of care and support with community caregivers towards the ill family members, in order to learn the skills on caring for an AIDS patient. Participation of family members during the caring process by the community caregivers also influences the time that the community caregiver spends with each family. This was also evident from the frequency of visit i.e. table 4.9. Community caregivers spent less hours in a family where the family members assisted them especially during the bathing of the patient because it requires a lot of activities i.e.

putting on a fire to warm the water, undressing and dressing the patient after the bath, brushing the patient's teeth, nail and hair care, dressing of wounds if any, and making the patient's bed.

The following table indicates whether patient's family members assist community caregivers in bathing and feeding the patient during the community caregivers' visit to the families (the data presented in this table is based on the interview with community caregivers).

Table 4.21: The extent in which family members assist community caregivers

Assistance by family members	**n**	**%**
Always	18	36
Sometimes	23	46
Never	9	18
Total	50	100

The table below indicates whether community caregivers ask family members for assistance. The data is based on interviews with the community caregivers.

Table 4.22: Request for assistance from family members by the community caregivers based on the community caregivers' perspectives

Asking for assistance	**n**	**%**
Yes	39	78
No	11	22
Total	50	100

The following table 4.23 indicates whether the community caregivers asked assistance from family members when providing services to the patients (the data presented in this table is based on interviews with family members).

Table 4.23: Request for assistance from family members by the community caregivers based on the family members' perspectives

Whether community caregiver asked family members for assistance with the care of the patient	**n**	**%**
Yes	41	82
No	9	18

Table 4.22 shows that 39 (78%) community caregivers indicated that they ask family members for their assistance when providing care to the ill patients; while table 4.23 shows that 41 (82%) of the families indicated that community caregivers ask for their assistance.

At least 41 (82%) of the family members indicated that they were involved in providing care for their ill family members with the community caregivers. However, the few families who indicated that community caregivers did not ask for their involvement felt that the community caregivers wanted to do the work by themselves. Some of these families indicated that the community caregivers were paid to do the work; hence they did not want to get involved. It was evident from this information that some family members believed that community caregivers were paid for rendering the community/home based care services. Community caregivers indicated that they were not remunerated for the services they were providing to patients.

The information presented in table 4.21 above shows that at least 41 (82%) of the respondents reported that family members assisted them either always or sometimes when they are providing care to the terminally ill patients i.e. bed bathing the patients or feeding the patients. This shows that most community caregivers involve family members when providing care and support to the ill patients. Table 4.22 also shows that 39 (78%) community caregivers indicated that they involve the families by asking their assistance when they arrive at each family.

The main reason given by the community caregivers who did not ask for the family assistance was fear of embarrassment should the family members refuse to offer assistance. These community caregivers felt that the assistance should come voluntarily. They also indicated that their patients pointed out to them that their family members felt that the community caregivers are paid to provide the care to the terminally ill patients and it is therefore the community caregiver's solely duty to perform such roles. Most community caregivers also highlighted that some families fear that they might contract the virus because they (the family members) did not have protective hand gloves to use when they need to dress the wounds of the ill persons. Most of the respondents who indicated that family members did not assist them in providing care for their patients also responded that they did not ask family members for their assistance. This could mean that the community caregivers did not involve such families. These families are misinformed with regard to remuneration of community caregivers. They thought that community caregivers were being paid to provide care and support to people living with HIV&AIDS. Awareness interventions need to be strengthened to ensure that communities are well informed about the volunteerism of community caregivers.

4.4.4 Discussion of patient's progress with community caregivers

The community/home based care programme encourages families to be involved in the caring of their ill family members. Community caregivers should engage families by discussing the progress that patients are making or lack thereof, with the families. This will enable the community caregivers to identify factors related to the progress made or lack of progress made by patients, and to recommend alternatives to families to sustain progress made by patients.

The following table indicates whether community caregivers discuss patient's progress with the family members:

Table 4.24: Discussion of progress made by patients with families

Whether community caregivers discuss patients' progress	**n**	**%**
Yes	41	82
No	9	18
Total	50	100

The information presented above in table 4.24 shows that 41 (82%) families indicated that their community caregivers discuss the patients' progress with them.

It is evident that most community caregivers are engaging the families when they are providing care and support to the patients.

4.4.5 Allowance to enter patients' room (based on interviews with community caregivers)

In order to determine the extent of access to patients' rooms, community caregivers were asked whether family members and the patients allow them to enter the patients' rooms freely. The findings will determine whether families and patients accept the community caregivers and if not, to provide recommendations for accepting the community caregivers based on the perspective of the family members and the patients.

The table below indicates whether family members allow the community caregivers freely to enter the patients' rooms to provide care and support. The information is based on the interviews with community caregivers.

Table 4.25: The extent in which families allow community caregivers' to enter patients' rooms based on interviews with community caregivers

Whether family members allow community caregivers into their homes	**n**	**%**
Always	38	76
Sometimes	12	24
Total	50	100

The researcher also seeks to establish whether the patients allow community caregivers to enter their rooms. Community caregivers need to get consent from the patients as well, to enter their rooms, even if family members gave consent to enter the patients' rooms.

The following table indicates whether patients or people living with HIV&AIDS allow community caregivers freely into their rooms to provide care and support. The information is based on the interviews with community caregivers.

Table 4.26: The extent in which patients allow community caregivers to enter their rooms

Whether patients allow community caregivers freely into their rooms	**n**	**%**
Always	38	76
Sometimes	12	24
Total	50	100

At least 38 (76%) of the community caregivers indicated that they are always allowed freely into the patients' room when doing home visits. The study found that families that always allow free access to patients' rooms have patients that allow community caregivers free access into their rooms as well. It was evident that the patients and their families were in agreement as far as the community caregivers were concerned.

Reasons given by community caregivers to substantiate their being allowed into the homes of people living with HIV&AIDS were related to culture. They indicated that the family members and patients made them aware of the families' beliefs and they did not interfere with them anymore e.g. when they found families burning traditional medicines in the patient's bedroom, the community caregivers would inform the family that they will visit the next day. From the 38 (76%) families that allow community caregivers freely into the patients’ rooms, 19 (38%) were from the Xitsonga ethnic group; 11 (22%) from Sepedi ethnic group while 8 (16%) were from iSiswati ethnic group. It is evident from this information that ethnic groups differ in allowing community caregivers to enter the patients’ rooms. A high percentage was found in families that were from the Xitsonga ethnic group, as compared to amaSwati. It is therefore important for community caregivers to understand the culture of each ethnic group and to respect it thereof.

Reasons given by those who were only allowed sometimes into the patients’ rooms were because of indigenous practices by family members i.e. when families are using traditional treatments, like burning some medicines inside the patient’s room.

Some of the patients’ did not want the community caregivers’ visit because caregivers insist that the patients take their pills. Community caregivers indicated that patients become weary to take their pills on a daily basis.

It is evident that families and patients do allow the community caregivers to enter the patients’ rooms to provide care and support to the ill patients. However, culture plays an important role for families to grant community caregivers free access to the patients’ rooms. It was evident that community caregivers were more accepted because they respected the culture of the families they were visiting. For community caregivers to be accepted by families and persons living with HIV/AIDS, it is important to know and respect the culture of each family they are providing care and support.

4.4.6 Infection control

The transmission of HIV is prevalent for families who do not have knowledge of HIV transmission. Such families could expose themselves to HIV infections without knowing it. For instance, a grandparent who sucks blood from his/her infected grand child who has injured him/herself, with a view to stop the bleeding. Families need to know that it is important to use protective gloves when they are cleaning and dressing the wounds of any person including AIDS patient. The gloves must be discarded immediately after use where children cannot access them. Sterilisation of utensils such as nail clippers, after cutting the nails of the patient is important because they can accidentally cut the flesh when cutting the nails.

The following table indicates whether family members understand about the infection control:

Table 4.27: Understanding of infection control

Whether family members understands about infection control	**n**	**%**
Yes	46	92
No	4	8
Total	50	100

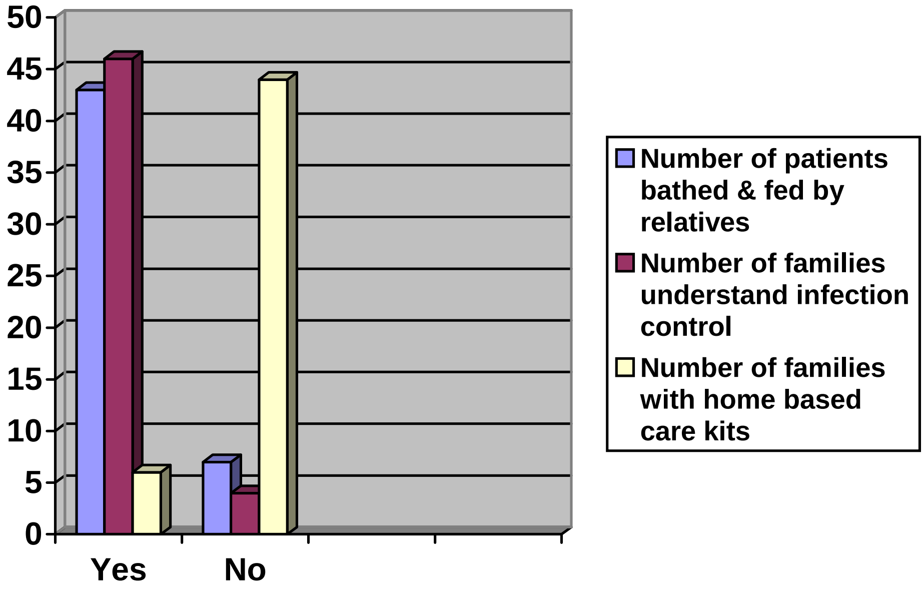
Table 4.28: The person that made family members to be aware of infection control

Who made family members to be aware of infection control	**n**	**%**
Nurse	6	13
Community caregiver	40	87
Total	46	100

Table 4.27 shows that 46 (92%) families have knowledge of how to prevent infection and understand about infection control. Table 4.28 shows that from the 46 families that indicated that they understand about the infection control, 40 (87%) of the families indicated that they were taught by the community caregivers when they visited the patients. Few of the families indicated that nurses at the local clinics taught them before they referred them to the community/home based care programme. The other 4 (8%) families that responded that they did not have an understanding about infection control indicated that they only knew that the virus was transmitted sexually. Although this is a very small number, it is important that every family knows about the infection control in order to be able to take precautions when providing care to their AIDS ill family members.

The following Figure 3 depicts the number of families bathing and feeding their ill family members during the absence of the community caregivers; the number of families understanding about infection control; and the number of families with home based care kits. The figure seeks to establish a relationship between the understanding of infection control by family members, the availability of home based care supplies such as examination gloves, and the provision of care and support to the ill family members during the absence of a community caregiver.

FIGURE 4.1: Number of families who bathe and feed their ill family members as well as the number of families understanding infection control



It is evident from this figure that although there is a huge number of families who do not have home based care supplies such as examination gloves, they do provide care and support to their ill family members. The study also shows that many families understand infection control methods. This knowledge base enables them to provide care to their ill family members in a safe way i.e. sterilising of sharp equipments after use.

4.5 THE LEVEL OF SATISFACTION, AND THE ATTITUDES OF FAMILY MEMBERS OF PEOPLE LIVING WITH HIV & AIDS TOWARDS COMMUNITY CAREGIVERS:

Fifty families of people living with HIV & AIDS participated in this section. Twenty-two families were drawn from Xitsonga ethnic group; sixteen were drawn from Sepedi ethnic group while twelve families were from iSiswati ethnic group. The characteristics of these families were outlined under the section: ‘Sampling’ table 3.1, page 43.

4.5.1 Familiarity with the community caregiver by family members

Community caregivers are recruited and selected based on their good standing in their communities. Due to financial constraints to run the community/home based care programme, community caregivers are mainly placed at their respective communities, to ensure that the sites do not direct most of its funds for the community caregivers’ transport to visit families. Placement of community caregivers in their respective communities can have an effect on the way in which families accept community caregivers. Especially when community caregivers are not of good standing and the families know about it. This section seeks to establish whether the familiarity to the community caregivers by family members has influenced the acceptance of community caregivers by the families.

The table below indicates whether family members knew the community caregiver who was visiting their families to provide care and support to the ill family member prior to the visits.

Table 4.29: Familiarity with the community caregivers

Whether family members knew the community caregiver	**n**	**%**
Yes	15	30
No	35	70
Total	50	100

At least 35 (70%) of the families participated in the study, did not know the community caregiver before he/she started visiting their families. In other words they did not know his / her credibility within their community. The families relied on the sources that linked them with the community caregivers i.e. nurses, and the project managers about the credibility of the community caregivers. Families indicated that when the nurses and project managers referred them to the community/home based programme, they further highlighted that the community caregivers were of good standing and are able to provide care and support to ill patients. Family members who knew the community caregivers prior to visiting their ill family members indicated that the community caregivers were of good standing in the community. They indicated that they would not have approved a community caregiver with a bad reputation. A bad reputation was defined as someone who is not able to look after his/her family, drinks too much alcohol, and has multiple partners (in a case of a man, when he is not married to these multiple partners). The information presented above indicates that credibility of community caregivers does influence families' decisions to accept the community caregivers.

Families who knew the community caregivers prior the first visit to the family were accepted because the families knew of their good standing in the community.

4.5.2 Referral system

For families to embrace the community/home based care programme, it is important for the referral system to fully explain the community/home based care programme. Having a stranger visiting one's family and becoming involved with the family can be threatening to the family. Community/home based care services need to be negotiated with the families, rather than imposed. Referral plays an important role in community/home based care programme. It serves as a point of entry to the relationship between the community caregivers and the families they are providing care and support, which could be long term.

The information presented in table 4.30 below indicates how families came to know the community caregivers and the community/home based care programme.

Table 4.30: Source of referral

Referral system	**n**	**%**
Hospital	9	18
Clinic	23	46
Department of Social Development's social workers	3	6
Community/home based care sites	15	30
Total	50	100

The table below indicates whether family members gave consent to the referral of the community caregiver to visit their homes to provide care and support to their ill family members. The information will help to determine whether the community/home based care programme was imposed to families or not, and to find out whether the families' consent or lack thereof, has influence on families accepting the community caregivers.

Table 4.31: Consent for referral

Whether family members consented to the referral	**n**	**%**
Yes	50	100
Total	50	100

The first visit to the family can be accompanied by feelings of uncertainty for both the family and the community caregiver. Because they both do not know what each party is expecting from the other. The research sought to determine whether community caregivers were formally introduced to the families on their first visit.

The following table depicts who introduced the community caregiver to the immediate families:

Table 4.32: Formal introductions of community caregivers with family members

Who introduced the family to the community caregiver	n	%
Community/home based care site	7	14
Nurse	11	22
Social Worker	2	4
Community caregiver her/himself	30	60
Total	50	100

The information presented in table 4.30 indicates that most of the family members were referred to the community/home based care programme by the nurses at the clinics. Families indicated that nurses informed them about the community/home based care programme at the clinics during consultations for their ill family members. The community/home based care site was found to be the second most referral system to refer patients for the community/home based care programme. The Department of Social Development's social workers was found to be the least referral system. The social workers provided the information on community/home based care services to families when the families approached the Department for material assistance. Families indicated that the community/home based care programme was explained to them. They were informed that community caregivers will be visiting their families to provide care and support services to their ill family member (services as outlined under the section: 4.3.6 services provided by community caregivers, page 77). Table 4.31 indicates that all families consented to the provision of community/home based care services to their ill family members. Families indicated that consent was given verbally.

Table 4.32 indicates that at least 30 (60%) families pointed out that community caregivers were not formally introduced prior their initial visit to the families as one family member said:

> “ We were sitting under the tree i.e. myself, grandmother and my sick brother who was sleeping next to our grandmother. We saw the lady coming to where we were sitting greeting us. At first we thought that she was selling something because she was carrying a bag with her. After the formal greetings she introduced herself, telling us that she was sent by the clinic to visit my sick brother. There was silence at first after she has spoken but then my grandmother welcomed her into the family”.

Families indicated that it is contravening their cultural practice when community caregivers are not introduced properly during their initial visit to the homes. There is a gap for the community/home based care programme to ensure that formal introductions between families and community caregivers are conducted prior the visit to the homes. This can be done by facilitating meetings between the community caregiver and the family concerned.

4.5.3 Influence of culture / family values and norms

Cultural sensitivity is necessary to provide quality and effective home based care to patients with HIV/AIDS and their families. Culture plays an important role in home based care because the patient's cultural practices will assume priority in his/her own home. According to a study conducted by Daigle et al (1999:271), it was found that most male and female Hispanics living with HIV/AIDS preferred folk healers and traditional remedies as compared to western medicines. For the programme to work effectively, it is important to be sensitive to patients' cultural differences.

Different cultural beliefs exist between the community caregivers and the families that they are providing care and support. Especially because some families and the community caregivers are not from the same ethnic group.

Table 4.33 and table 4. 34 below illustrate that culture / family values and norms influence service delivery by community caregivers. The information is based on the perspectives of both the community caregivers and the family members.

Table 4.33: The influence of culture based on perspective from community caregivers

Whether culture/family values and norms influence service delivery	**n**	**%**
Yes	50	100
Total	50	100

Culture plays an important role in the community caregivers' role towards the patients. All participants reported that most of the families receiving care from the sites believed in traditional healing. Most community caregivers indicated that the families' traditional beliefs sometimes interfere with their provision of care and support. When the condition of the patient becomes worse, the community caregivers will advice the family members to take patient to hospital but the family members would choose to take the patient to a traditional practitioner. The community caregivers felt that most of their patients' deaths were caused by the traditional medicines, because even when the patient was suffering from diarrhea he/she will still be given traditional medicine that causes diarrhea thus causing the patient to be even weaker than before. One community caregiver pointed out that the patients and their families believed that when diarrhea occurs, then it means that the traditional medicine is working and the disease is leaving the patient's body.

The respondents indicated that when they visit patients on a weekend, most families are often adamant to receive them in their homes with the fear that they might be coming from a funeral. It is common practice in the villages to bury their loved ones on Saturdays. Some families asked the community caregivers whether they are from the funeral, and if the answer is yes, they politely asked them not to enter the patient's room. This is based on their cultural belief that a person who is from a funeral is ominous towards a very sick person and this can cause pre-mature death. Most community caregivers felt that the families were treating them unfairly because families accepts services from black nurses at the hospitals who are providing care to patients irregardless of whether the nurses come from funerals or not.

4.5.4 The influence of culture based on perspectives from family members

The table below indicates whether families think that community caregivers were aware of the family culture, values and norms:

Table 4.34: Community caregivers that were aware of family culture

Whether community caregiver is aware of the family culture	**n**	**%**
Yes	50	100
Total	50	100

All families participated in the study reported that the community caregivers were aware of their culture, values and norms. Family members had made the community caregivers aware of their culture, values and norms.

4.5.5 Respect for family's culture, values and norms

The table below indicates whether families think that community caregivers did respect the family's culture, values and norms:

Table 4.35: Community caregivers that respect family's culture, values and norms

Whether community caregivers respect family's culture	**n**	**%**
Yes	44	88
No	6	12
Total	50	100

The study showed that 44 (88%) of the participatory families in the study indicated that the community caregivers respected the family's cultural beliefs, norms and values. When asked how this respect was shown, they explained that they have discussed with the community caregivers about the family cultural practices. Community caregivers did not visit the patients when they are coming from funerals. Community caregivers did not inhibit them to use indigenous or traditional practices in respect of their ill family members. One family member said:

> "At first the community caregivers did try to inhibit us from taking our patient to the traditional doctors saying that the traditional medicines will only make the patient worse. But we reminded the community caregiver that our family had been going to traditional practitioners since we were born and they got cured from ailments. Some diseases

do not want doctors at hospitals….”.

4.5.6 Association of community caregivers with HIV&AIDS by neighbours

Daigle et al (1999:268), in their research found that most health-care nurses were designated as AIDS nurses by communities. This designation makes it difficult for families to allow these health-care nurses to enter their homes. Families fear that when they allow the health-care workers into their homes, communities will conclude that they have an AIDS patient and therefore stigmatise them. The designation of health-care workers as AIDS nurses hampered with the provision of care and support to patients by health-care workers.

The information presented below in table 4.36 seeks to establish whether families feel that neighbours associate the community caregivers with HIV&AIDS and whether the association affect their acceptance of the community caregivers. The table below shows the number of families feeling that neighbours associated the community caregivers with HIV&AIDS.

Table 4.36: Association of community caregivers with HIV&AIDS

Whether neighbours associated community caregivers with HIV&AIDS	**n**	**%**
Yes	31	62
No	19	38
Total	50	100

The table above indicates that most families responded that communities associate the community caregivers with HIV&AIDS. Families indicated that community caregivers are branded as “HIV/AIDS people”. There is an assumption that every family that is visited by the community caregivers have an AIDS patient. Although communities are making these assumptions, families do allow the community caregivers’ services for the ill family members. There were 19 (38%) families that indicated that their community caregivers are not associated with HIV&AIDS i.e. designated as carers for people with HIV&AIDS. These families indicated that the community caregivers are known to be caring for every sick person regardless of the type of diseases. The community caregivers also provide care to persons suffering from other diseases including tuberculosis and cancer. It is therefore important for the community/home based care programme to broaden its scope to ensure that community caregivers do not focus only on AIDS patients. This will eliminate the branding of community caregivers as “HIV/AIDS people”.

4.5.7 Satisfaction with the conduct of community caregivers

The table below indicates whether family members were satisfied with the conduct of the community caregivers:

Table 4.37: Satisfaction with the community caregivers' conduct

Satisfied with conduct of community caregivers	**n**	**%**
Yes	44	88
No	6	12
Total	50	100

The respondents who indicated that they were satisfied with the conduct of the community caregivers, alluded the following to substantiate their responses:

- The community caregivers maintained confidentiality about the affairs of the families.
- The community caregivers showed support and love towards the ill family members.
- They respected the families' decisions in respect of cultural beliefs and norms.
- The advices given by the community caregivers gave the patients and their families hope.

The respondents who indicated that they were not satisfied with the community caregiver said that the community caregivers do not respect the families' decisions in relation to cultural beliefs i.e. when they wanted to take their ill family members to traditional practitioners. They recommended that the community/home based care sites should educate the community caregivers about their culture before they visit families. It is evident that although these few families indicated that they are not satisfied with the community caregivers providing care and support to their ill family members, they indicated that they were satisfied with the community/home based care services.

4.5.8 Acceptance of community caregivers by patients

The table below indicates the acceptance of community caregivers by the patient as perceived by the family members:

Table 4.38: Patients that accept community caregivers

Whether Patients Accept Community Caregivers	**n**	**%**
Yes	45	90
No	5	10
Total	50	100

The study showed that (45) 90% of the families felt that their ill family members accepted the community caregivers well. The patients trust the community caregivers because they were able to talk freely with the community caregivers especially when the community caregiver is of the same sex with the patient.

Patients were able to take their medication when community caregivers asked them to. They liked the community caregivers for bringing them food parcels.

Those who felt negatively towards the community caregiver, mentioned reasons that the community caregivers made them drink pills yet the pills did not make them feel better, and when the patient was expecting food parcels from the community caregiver and the community caregiver did not bring the food parcels.

4.5.9 Satisfaction with the community caregivers

The table below indicates whether families were satisfied with the community caregiver visiting their homes to provide care and support to their ill family members:

Table 4.39 Families that were satisfied with the community caregivers

Whether family members were satisfied with the community caregivers	**n**	**%**
Yes	44	88
No	6	12
Total	50	100

The study found that 44 (88%) families were satisfied with the community caregivers' services provided to their ill family members i.e. bed bathing, feeding, lay counselling and teaching them how to live with their patients. Reasons given by the families included the following:

- It is less expensive for the families to have their ill family members cared for at home as compared to at the hospitals where they would need to fare their transport to visit the patients.
- It is stress alleviating to have someone who cares about their loved ones and assist them unconditionally, regardless of blood relations. It provided the families with emotional support.
- They get immediate assistance from local clinics when they took their ill family members to the clinics accompanied by the community caregivers because the nurses knew the community caregivers.
- Bed bathing their ill family members is exhausting especially because they had to turn the patients. With the presence of the community caregivers, it becomes easier since they help each other.
- The community caregivers provide them with food parcels and food supplements for the patients.
- The patients had good working relationships with the community caregiver, most patients did not want to take their pills or food but when the community caregiver was available they were able to take their pills and their food.

Reasons given by families who were not satisfied with the community caregivers were:

- When a community caregiver provided care to a patient of the opposite sex especially when a male community caregiver is supposed to bed bath a female patient.

- Community caregivers not respecting the families' cultural beliefs e.g. when the patient had to take traditional medicines and the community caregivers advising them not to take these medicines.
- Families believing that a very sick person should not be exposed to a woman who has had abortion, miscarriage, is menstruating, just conceived a child, who has had sex the previous night, or is from a funeral. Family members believed that these can exacerbate sicknesses and can even cause pre-mature death for the patient.
- Communities associating community caregivers with HIV & AIDS. Families were not comfortable with the community caregivers' visits because people will think that their ill family members were dying of AIDS and the families did not want people to know about their patients' HIV status.

4.5.10 Recommendations made by family members for them to accept community caregivers to visit their homes

In terms of community caregivers being accepted, family members alluded that the community caregivers should respect their cultural beliefs and not impose their beliefs on the patients. Community caregivers should stay away from the ill family members when they are from funerals, had miscarriage, abortion. Some families pointed out that in order for the community caregivers to visit their ill family members, they can wash their hands from a concoction of traditional medicine when they are from funerals. This will remove the "darkness" which the families believe it is associated with funerals.

4.6 SUMMARY

The results of the study provided comprehensive information about the community/home based care programmes within the three sites selected i.e. Maviljan, Hluvukani and Cunningmore community/home based care site. It also generated an amount of information about how the immediate families experienced the community/home based care services towards their AIDS ill family members. The loyalty of families towards their community caregivers as well as that of community caregivers towards the project managers of the community/home based care sites were controlled to elicit honest responses.

The following chapter concludes the study with a discussion of the study in general, research conclusions and the recommendations proffered.

CHAPTER FIVE

RESEARCH CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

This chapter commences by providing a discussion of the study and thus continues to indicate whether the research findings fulfilled the research objectives initially outlined for the purpose of this research. The chapter will also outline recommendations proffered for the effective implementation of community/home based care services towards people living with HIV&AIDS.

5.2 DISCUSSION

The HIV & AIDS pandemic presents community caregivers with a huge task of providing care and support services to terminally ill patients. The community caregivers themselves were coming from a poor socio-economic background. Their tasks expose them to risks of contracting the deadly virus. The lack of stipend and home-based care kits which are not refilled regularly inhibited them to provide optimal services towards the AIDS ill patients and come in conflict with their moral obligation to do the best for the infected persons. Despite all these impeding factors, most community caregivers indicated that they experience satisfaction from helping the sick.

The study found that most family members were involved in the provision of care and support to their ill family members. There were many families that assisted the community caregivers during the bathing and feeding of ill family members. Families also continued to provide care and support to their ill family members during the absence of the community caregivers. Involvement of family members to provide care was seen as relieving the caregivers i.e. giving them some break knowing that the families were giving proper care to the patients. It also gives community caregivers time to visit patients who do not have extended families to look after them, as well as relieving children and youth heading households and giving them the opportunity to attend school while their sick siblings are cared for by community caregivers.

Although there were few numbers of minor children and elderly people providing care to ill family members, this is an indication that roles have changed in the families and compel those few elderly people and minor children to provide care to people living with HIV & AIDS. Both families and community caregivers highlighted the need for community caregivers to work with families in the provision of care. Certain roles were mentioned as being easy to be fulfilled when working together e.g. bed bathing a patient which requires a lot of activities i.e. making the fire to warm the water, the actual bathing which requires turning the patients, brushing of teeth, wound care etc.

Community caregivers are providing care and support to the very sick and dying persons and as a result they are prime candidates for the negative effects of palliative care related stress. They experience emotional strain quite often. They spend long hours in the midst of suffering of their dying patients. All community caregivers indicated that they receive debriefing services. The debriefing services they are provided with helped them to deal with those emotional crippling effects of care giving in order to allow continuation of care and support towards the terminally ill patients and their families. However, services of local pastors are important in debriefing but they were not sought for by the community/home based care sites. The study found that local social workers' services for debriefing community caregivers were not fully tapped by the sites. Group counselling by social workers can be of great benefit to the community caregivers and also save time as compared to individual counselling.

Community caregivers indicated that the death of a patient and a dying patient is demotivating them when they are providing care and support services to their patients. It is believed by health professionals that the Anti-Retroviral Drugs will help people living with HIV & AIDS to live longer and manages opportunistic infections. The rollout of these Anti-Retroviral Drugs in the Bohlabela district was at one hospital only i.e. Mapulaneng hospital. Most patients were not yet put on these drugs. However the compliance and adherence to these drugs in the districts was not yet established especially because when patients' CD4 count cells comes to be above 200 the Social Security System is to cease the disability grant. The question is whether families and patients from low-socio economic status will continue or encourage patients to take the drugs knowing that their health improvement comes with a consequence of loosing the disability grants.

Most community caregivers had received training on care and support of people living with HIV & AIDS. All the three sites were confronted with the high staff turn over which called for new recruits who did not have previous training on the care and support to people living with HIV & AIDS. This left a financial burden on the community/home based care sites to train the new recruits to help them confront the day-to-day challenges of their work especially with lay counselling. The findings highlighted a gap in the three sites that there is a high need of training the new recruits as soon as they are recruited to prepare them to be able to provide counselling and be able to answer questions which families might raise. The community caregivers are expected to be a resource agent in terms of referring patients to a variety of resource agencies; hence the prior training was outlined as imperative.

A very large percentage of community caregivers indicated that they were satisfied with the kind of services they provided to people and families infected and affected by the pandemic. They were satisfied with all of their roles especially when they saw positive results of what they did to families and their AIDS ill patients. The findings also highlighted common misconceptions in terms of families' cultural beliefs, norms and values, where most community caregivers imposed their beliefs to the families. Community caregivers were aware through the training they received and attending workshops that there is no cure for the pandemic and that symptoms like diarrhoea weakens the patients, however this contradicted with the families' beliefs that traditional medicines could cure the 'disease' especially when the concoction caused diarrhoea then it implies the disease was leaving the patient's body.

The study found that culture played an important role in the community/home based care programme. Both families and community caregivers indicated that the respect of family’s culture promote acceptance of community caregivers by the families. Majority of the families indicated that community caregivers respected the family’s cultural beliefs and they were satisfied with the community caregivers’ conduct. Few families were torn between as to whether to accept the community caregivers as they felt that their cultural beliefs were being compromised because of the community/home based care program. They felt that it was too risky to have community caregivers visiting their very sick patients yet they might be from funerals, might have had an abortion or a miscarriage, had sex the previous night or had just conceived a child.

Community caregivers on the other hand felt that families were discriminating against them in the sense that at hospitals, families do allow black nurses to care for their ill family members without judging them on whether they were from funerals or not. Community caregivers felt that they had an obligation to provide care and support to ill members although there were few families that denied them access to these patients sometimes based on these cultural beliefs.

The findings also highlighted that community caregivers experienced the same kind of cultural beliefs from all three ethnic groups in the district where they are providing care and support services i.e. Xitsonga ethnic group, Sepedi ethnic group and iSiswati ethnic group. However, most of the families pronouncing these cultural barriers were from the Xitsonga and Sepedi ethnic groups.

There was a relationship between the level of training of community caregivers and the respect of families' cultural beliefs and norms. Most of the families that indicated that the community caregivers did not respect their culture had community caregivers who indicated that they did not receive training on care giving.

The study identified a gap in that the training of community caregivers should involve cultural aspects, local beliefs and local language. The issue of adopting a non-judgemental attitude should also be mainstreamed in the training of community caregivers to curb biased attitudes towards families' practices when community caregivers visit families.

The study found that community / home based care services were accepted by most families who were having ill family members at home. Most families indicated their willingness to have their ill family members being cared for by community caregivers at home rather than at hospital because of the package these kinds of services come with i.e. taking care of ill family members at home relieved families of financial burden associated with caring of ill family members at the hospitals. Families did not have to worry about bus or taxi fare to visit their loved ones at the hospitals. The presence of a caring community caregiver also relieved the family from emotional stress of having a very sick person at home, because they were able to talk about their fears in terms of the dying family member and could plan about what will happen to the dying person's children with the community caregiver. Most families also indicated that their ill family members accepted the community caregivers' services as well, especially when the community caregiver is of the same sex as the patient.

Many families indicated that the community associate the community caregivers with HIV&AIDS. When community caregiver visits a family, community members make assumptions that the ill family member in that particular family is HIV positive. The study found that the association of community caregivers with HIV&AIDS does not hinder the families to accept the community caregivers into their homes to provide care and support to their ill family members. Although there were few families that indicated that they were not comfortable to have a community caregiver visiting their ill family members with the fear that the community will automatically conclude that their ill family members were dying of AIDS, this also did not hinder such families to allow the community caregivers to enter their homes. These fears and prejudices associated with HIV & AIDS undermine the opportunity to offer people living with the pandemic the care and compassion they deserve.

5.3 RESEARCH CONCLUSIONS

The study was an exploratory one that aimed at fulfilling three objectives. The objectives are as follows:

1.3.1 To measure the level of satisfaction of family members of people living with HIV&AIDS towards community/home based care services.

1.3.2 To unpack salient issues underlying the perceptions and attitudes of family members of people living with HIV&AIDS towards community caregivers providing care to these patients.

1.3.3 To proffer recommendations concerning policy of community/home based care programme and its impact in the community for programme development.

5.3.1 ***To measure the level of satisfaction of family members of people living with HIV&AIDS towards community/home based care services.***

The research results were highly positive. Most of the family members were highly satisfied with the services of the community caregivers. People living with HIV&AIDS and their families embraced the community/home based care program. Although most of the family members indicated that they were not consulted about the choice of a particular community caregivers, most of them reported that they did not have any regrets with the community caregivers chosen for them. If given the latitude to choose, they would still choose the same community caregiver. Many families indicated that bathing and feeding a bed-ridden person was cumbersome, however with the assistance of the community caregivers such encumbrance was alleviated.

Most families accepted the idea of having their ill family members to be cared for by community caregivers at home rather than at hospital because of the package these kinds of services come with i.e. taking care of ill family members at home relieved families of financial burden associated with caring of ill family members at the hospitals. Families did not have to worry about bus or taxi fare to visit their loved ones at the hospitals. The presence of a caring community caregiver also relieved the family from emotional stress of having a very sick person at home, because they were able to talk about their fears in terms of the dying family member and could plan what will happen to the dying person’s children with the community caregiver.

Results indicated that most families were satisfied with the conduct of the community caregivers. The community caregivers’ maintaining of confidentiality of the families’ affairs from the community yielded more acceptance by the family members. Families also accepted community caregivers because they were able to show love and support to their ill family members.

Most families indicated that being linked to a community/home based care site awarded them with an opportunity to receive food parcels and food supplements. The community/home based care sites furnish the Department of Welfare with list of patients that are poor for further assessment by social workers. Social workers conduct assessment to ascertain whether the patients qualify for the food parcels or food supplements. The frequency on the provision of the food parcels and the food supplements depends on the availability. It can be said that on average the frequency is quarterly. Families also indicated that they got immediate assistance at local clinics when community caregivers accompanied them, as opposed to when they visited the clinics by themselves. Families take their ill family members to clinics when their medical condition gets complicated.

The majority of the families also indicated that the availability of the community caregivers at home encouraged their ill family members to take medication. This was because the patients perceived the community caregivers as helpers and they had trust in them. Even their reluctant patients were wiling to take their pills when the community caregiver was present.

A very large number of the families indicated that the community caregivers respected the families' decisions regarding culture, values and norms for example, families indicated that community caregivers did not inhibit them to use traditional practices with regard to their ill family members. The more the community caregivers respected and adopted a non-judgemental attitude towards families' cultural beliefs, norms and values, the more the families accepted the community caregivers. This was showed by the reasons provided by the few families who indicated that they were not satisfied with the community caregivers. Their dissatisfaction was related to community caregivers not respecting their cultural beliefs i.e. families did not want the community caregivers to visit their ill family members when they were coming from a funeral. This is confirmed by Kadushin

(1990: 305) when he elaborates the importance of being aware of individuals' cultural milieu and to be sensitive about it when working with individuals.

5.3.2 ***To unpack salient issues underlying the perceptions and attitudes of family members of people living with HIV&AIDS towards community caregivers providing care to these patients.***

The research findings were able to unpack some important issues underpinning the families' perceptions and attitudes towards community caregivers. The respect of family's cultural beliefs, values and norms appeared to be a very imperative aspect for families to embrace the community/home based care program. Families who were satisfied with the community/home based care services highlighted the fact that community caregivers were not interfering with the family's cultural beliefs. Families who were not satisfied with the community/home based care services also highlighted that community caregivers were interfering with the family's cultural beliefs.

All families participated in the study indicated that they have made the community caregivers aware of the family's cultural beliefs. Community caregivers also indicated that they were aware of the family's cultural beliefs, values and norms. This was to ensure that community caregivers were non-judgemental towards families' traditional practices.

It became apparent from the results that communities had drawn an association between the community caregivers and the HIV&AIDS. According to the family members, communities assumed that every family that was visited by the community caregiver had an AIDS ill person. However, families allowed the community caregivers to visit their homes. Most families recommended that communities need to be educated that community caregivers also provide care and support to ill persons not infected by the HIV&AIDS.

The conduct of community caregivers also determined their acceptance by the families. It was apparent that families did not want the community caregivers to discuss the family affairs outside the families with the communities. Most families acceptance of the community caregivers was based on the trust they were having towards the community caregivers because of the confidentiality they were keeping.

The distribution of food parcels and food supplements to families with AIDS ill members by community caregivers also played a major role in eliciting positive attitudes by families towards community caregivers. Most families indicated their appreciations towards the community caregivers for providing them with food parcels and food supplements. They alluded that it was a lot easier for them to get food parcels because of the community caregivers who brought them when they were visiting the families.

5.3.3 ***To proffer recommendations concerning policy of community/home based care programme and its impact in the community for programme development.***

The recommendations made are discussed below.

5.4 RECOMMENDATIONS

The following recommendations are proffered:

1. Department of Health and Welfare should increase funding for community / home based care sites to cater for training of new recruits and to provide stipend for community caregivers. The research findings indicated that the families which were not satisfied with the community caregivers as they were not respecting their cultural beliefs, were mostly having community caregivers allocated to them who indicated that they were not trained as caregivers. The study also shows that there is a high turn over of community caregivers due to lack of stipends. This leaves the sites with a huge responsibility of recruiting new community caregivers who need training. Training of community caregivers is important to ensure that families embrace the community/home based care program optimally.

2. Community / home based care sites should engage in fundraising activities to be able to sustain their sites. The study indicated that the community/home based care sites did not receive adequate funding from the Department of Health and Welfare to enable them to conduct training of community caregivers. It is therefore

recommended that the Department’s policy should include providing the sites with necessary skills for fundraising. This would enable the community/home based care sites to deliver effective and efficient services for the families.

3. Provision of home-based care kits, food parcels and food supplements should be strengthened to adequately address the needs of the families and their ill family members. The results of the study indicated that most families applauded the community/home based care programme for providing patients that are poor with food parcels and food supplements. However, the supply of such food parcels was irregular. The study also indicated that most families did not have home-based care kits. For families to assist the community caregivers in the provision of care to the AIDS ill patients and to continue such services when the community caregivers had left, such home-based care kits are essential.

4. Formalizing the introductions of community caregivers to family members and the patients by the community / home based care sites. This should be stipulated as a standard practice in the Learner Handbook for the Training of Home/Community Based Caregivers (2001) developed by the Department of Health. The results indicated that most families were not formally introduced to the community caregivers. The community caregivers introduced themselves when they visited the families for the first time. This will enable the families, the patients, and the community caregivers an opportunity to talk about the expectations of each party to ensure that the community/home based care services are rendered optimally.

5. Mainstreaming the Home / Community based care training manual to incorporate the local cultural beliefs, values and perceptions to understand how the socio-cultural framework operates in a particular context. Training packages should also include skills such as non-judgmental attitudes to enable community caregivers to allow families to make their own decisions with regard to their cultural beliefs. Families who indicated that the community caregivers did not respect their culture explained that the community caregivers interfered with them when they wanted to take their ill family members to traditional practitioners.

6. Community support to people living with HIV&AIDS and the community/home based care programme must be mobilized to alleviate association of community caregivers with HIV & AIDS. The findings of the study indicated that families believed that communities were forming an association between the community caregivers and HIV&AIDS. When a community caregiver visits a family, communities conclude that the patient is infected by HIV. It is thus envisaged that community education and encouraging community caregivers to provide care and support to all ill persons, irrespective of the HIV infection, will alleviate stigma and the association of community caregivers with the pandemic.

7. Families should be involved in the care and support of their ill family members to offer patients the care and compassion they need. The research findings indicated that many families were involved in the provision of care by the community caregivers. However, the few families that were not involved indicated that community caregivers did not involve them and therefore felt that it was solely the responsibility of the community caregivers to bath or feed the patients.

Especially because families see the community caregivers as persons that are paid for providing care and support to the patients.

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APPENDIX A

QUESTIONNAIRE ONE: COMMUNITY CAREGIVERS

PERCEPTIONS AND ATTITUDES OF FAMILY MEMBERS OF PEOPLE LIVING WITH HIV AND AIDS TOWARDS COMMUNITY CAREGIVERS.

(To be completed by community caregivers)

IDENTIFICATION	
PROVINCE:	LIMPOPO
DISTRICT:	BOHLABELA
VILLAGE:	
HOUSEHOLD NUMBER:	
NAME OF INTERVIEWER:	
DATE OF INTERVIEW:	

SECTION A: LEVEL OF TRAINING OF COMMUNITY CARE GIVERS

(To be completed by community caregivers)

RESPONDENT'S IDENTIFYING PARTICULARS

Name:……………………………………………….

Place:………………………………………………..

Age:………………………………………………….

Gender:………………………………………………

Marital Status:……………………………………….

1. What is your highest qualification? ✓ (Tick the appropriate box)	1. Below Grade 3 [ ] 2. Grade 3 to Grade 7 [ ] 3. Grade 8 to Grade 10 [ ] 4. Grade 11 to Grade 12 [ ] 5. Post Matric [ ] 6. Other [ ] (Specify)………………………………….
2. Did you receive any training as a community caregiver?	Yes [ ] No [ ]
2.1 If Yes, who provided the training?	1. NGO [ ] 2. Government [ ] 3. University [ ] 4. Private Trainer [ ] 5. Other NGO's [ ] 6. Other [ ]

	(Specify)…………………………………..
2.2 How long was the training?	1. One week [ ] 2. Two weeks [ ] 3. Other [ ] (Specify)…………………………………..
2.3 Indicate the type of training received. (Multiple responses allowed)	1. Home based care [ ] 2. Counseling [ ] 3. Palliative care [ ] 4. Child and Youth care [ ] 5. HIV & AIDS training [ ] 6. TB/DOTS training [ ] 7.Other [ ] (Specify)…………………………………..
2.4 Is the training you received relevant and enhancing your service delivery?	1. Yes [ ] 2. No [ ]
2.5 If no, please substantiate your answer.	……………………………………………... ……………………………………………... …………………………………………… ……………………………………………
3. Did you receive a certificate after completing the training?	1. Yes [ ] 2. No [ ]
4. Do you receive a stipend?	1. Yes [ ] 2. No [ ]
4.1 If yes, what is the amount of stipend given to you?	1. Yes [ ] 2. No [ ]

SECTION B. SREVICE DELIVERY

(To be completed by community caregiver)

<table>
<tr><td>1. How long have you been a community caregiver?</td><td>1. Less than six months [ ]
2. Six to twelve months [ ]
3. One year to Two years [ ]
4. Two years to three years [ ]
5. Other [ ]
(Specify)…………………………………</td></tr>
<tr><td>2. Are you providing services to people living with HIV and AIDS/?</td><td>1. Yes [ ]
2. No [ ]
(If yes, please answer questions 2.1 to 2.10 below)</td></tr>
<tr><td>2.1 Write the breakdown of patients as follows:</td><td><table><tr><td>Adults male</td><td>Adults female</td><td>Children male</td><td>Children female</td><td>TOTAL</td></tr><tr><td></td><td></td><td></td><td></td><td></td></tr></table></td></tr>
<tr><td>2.2 How many times do you visit the same patient per week?</td><td>1. Once [ ]
2. Twice [ ]
3.Thrice [ ]
4. Other [ ]
(Specify)………………………………………….</td></tr>
<tr><td>2.3 List the type of services you are providing to the patient.</td><td>……………………………………………………
……………………………………………………
……………………………………………………</td></tr>
</table>

2.4 Who referred the patient(s) to you? (Multiple responses allowed)	1. Hospital [ ] 2. Clinic [ ] 3. Social Welfare [ ] 4. Other [ ] (Specify)……………………………………….
2.5 Indicate in the box provided, the number of patients who are… (Multiple responses allowed)	1. Head of the family ☐ 2. Breadwinner ☐ 3. Have children under the age of 18 as their primary caregivers ☐ 4. Have adults as their primary caregivers ☐ 5. Have elderly (aged) people as their primary caregivers ☐ 6. Do not have relatives as primary caregivers and solely depend on community caregivers ☐
2.6 Do you have home based care kits?	1. Yes [ ] 2. No [ ]
2.7 If yes, who supplies you with the kits? (Multiple responses allowed)	1. Provincial Department of Health and Welfare [ ] 2. National Department of Health [ ] 3. National Department of Social Development [ ] 4. Own kit [ ] 5. NGO [ ] 6. Other [ ] (Specify)……………………………………

2.8 Are the home-based care kits refilled regularly?	1. Yes [ ] 2. No [ ]
3. Do you get debriefing services?	1. Yes [ ] 2. No [ ]
3.1 If yes, who provides the debriefing services?	1. NGO [ ] 2. Social Workers [ ] 3. Nurses [ ] 4. Other [ ] (Specify)……………………………………………
4. How were you recruited as a community caregiver?	1. Recommended by community [ ] 2. Recruited through media [ ] 3.Word of mouth [ ] 4. Self [ ] 5. Other [ ] (Specify)……………………………………………
5. Does culture/ family values and norms influence your service delivery?	1. Yes [ ] 2. No [ ]
5.1 If yes, please elaborate how it influences your service delivery.	……………………………………………………... ……………………………………………………... ……………………………………………………...
6. Are you satisfied with your duties as a community	1.Yes [ ] 2. No [ ]

caregiver?	
6.1 If no, explain why?	…………………………………………………………... ………………………………………………………….. …………………………………………………………..
7. What is it that you enjoy most as a community caregiver?	………………………………………………………….. ………………………………………………………….. …………………………………………………………..
8. What demotivates you when rendering your services?	…………………………………………………………… …………………………………………………………… …………………………………………………………… ……………………………………………………………
9. Any recommendations you would like to make for the improvement of service delivery.	…………………………………………………………… …………………………………………………………… …………………………………………………………… …………………………………………………………… ……………………………………………………………

SECTION C: INVOLVEMENT OF EXTENDED FAMILIES IN HOME BASED CARE.

(To be completed by community caregivers)

1. When you visit the patient, do you find him/her bathed?	1. Yes [ ] 2. No [ ]
1.1 If yes, who bathed the patient?	**<u>Specify</u>** relationship………………………………and Age………………………………………….
1.2 If not, please explain why.	…………………………………………………. …………………………………………………. ………………………………………………….
2. When you visit the patient, do you find him/her fed?	1. Yes [ ] 2. No [ ]
2.1 If yes, who fed the patient?	**<u>Specify:</u>** Relationship………………………………..and Age…………………………………………….
2.2 If no, please explain why?	……………………………………………………. ……………………………………………………. …………………………………………………….
3. When you visit the patient, do you find his/her room	1. Yes [ ] 2. No [ ]

cleaned?	
3.1 If yes, who cleaned the patient’s room?	**Specify:** Relationship……………………………………. Age………………………………………………
3.2 If no, please explain why?	…………………………………………………….. …………………………………………………… ……………………………………………………
4. Does the patient’s family members assist you in bathing and feeding the patient during your visit to the family?	1.Always [ ] 2. Sometimes [ ] 3. Never [ ]
5.Do you ask the family members to assist you with the patient during your visits to the family?	1.Yes [ ] 2. No [ ]
6. Do the family members have home based care kits?	1. Yes [ ] 2. No [ ]
7. Do the family members understand about infection control?	1. Yes [ ] 2. No [ ]
7.1 If yes, who made them aware of infection control?	1. Nurses [ ] 2. You [ ] 3. Other [ ]

	(Specify)……………………………………..
8. Does the family allow you freely into their homes to provide home based care services to their family members?	1. Always [ ] 2. Sometimes [ ] 3. Never [ ]
8.1 If the answer is either (2) or (3), please substantiate it.	…………………………………………………… …………………………………………………… …………………………………………………… …………………………………………………….. …………………………………………………….. ………………………………………………………
9. Does the patient allow you freely into his /her room?	1. Always [ ] 2. Sometimes [ ] 3. Never [ ]
9.1 If the answer is either (2) or (3), please substantiate.	…………………………………………………… …………………………………………………… …………………………………………………… …………………………………………………… ……………………………………………………... ………………………………………………………

APPENDIX B

QUESTIONNAIRE TWO: EXTENDED FAMILIES

SECTION A: LEVEL OF SATISFACTION OF EXTENDED FAMILIES OF PEOPLE LIVING WITH HIV AND AIDS.

(To be completed by family members of people living with HIV and AIDS.)

RESPONDENT'S PARTICULARS:

Name……………………………………………..

Age……………………………………………….

Gender……………………………………………

Address…………………………………………..

……………………………………………

Relationship to the patient…………………………….

1. What is the type of your dwelling?	1. Mud house [ ] 2. Cement-bricked house [ ] 3. Face-bricked house [ ] 4. Other [ ] (Specify)…………………………………
2. Indicate the number of people in the household.	…………………………………………..
3. How long have you been living together with this patient?	…………………………………………..
4. Does the house belong to the patient?	1. Yes [ ] 2. No [ ]

5. Does the patient share his/her bedroom with any member of the family?	1. Yes [ ] 2. No [ ]
6. If yes, who does the patient shares his/her bedroom with (in terms of relationship).	1. Child [ ] 2. Husband [ ] 3. Aunt [ ] 4. Uncle [ ] 5. Mother [ ] 6. Father [ ] 7. Wife [ ] 8. Other [ ] (Specify)………………………………….
7. How well do you think your living arrangements satisfy your needs for comfort, convenience and safety?	1. Very well [ ] 2. Fairly well [ ] 3. Not too well [ ] 4. Not at all [ ]
8. Did you know the community caregiver who is visiting your patient, before?	1. Yes [ ] 2. No [ ]
9. Who referred the community caregiver to your home?	1. Hospital [ ] 2. Clinic [ ] 3. Social Welfare [ ] 4. NGO [ ] 5. Other [ ] (Specify)……………………………………

	………………………………………………..
10. Did you consent for this referral?	1. Yes [ ] 2. No [ ]
11. Were you given latitude to choose this particular community caregiver?	1. Yes [ ] 2. No [ ]
11.1 If no, would you have chosen this particular caregiver if given latitude?	1. Yes [ ] 2. No [ ]
12. Who introduced the community caregiver to the family during the initial visit?	1. NGO [ ] 2. Nurse [ ] 3. Social worker [ ] 4. Him/Herself [ ] 5. Other [ ] (Specify)…………………………………
13. What services does the Community caregiver offer your patient? (multiple response allowed)	1. Bathing [ ] 2. Feeding [ ] 3. Counseling [ ] 4. Family support [ ] 5. Other [ ] (Specify)……………………………. ……………………………...
14. Does the community caregiver ask you to assist him/her when providing such services to your	1. Yes [ ] 2. No [ ]

patient?	
15. Does the community caregiver discuss patient’s progress with any of the family members?	1. Yes [ ] 2. No [ ]
16. Are you satisfied with the community caregiver’s services?	1. Yes [ ] 2. No [ ]
16.1 If no, please give your recommendations.	…………………………………………… ………………………………………….. ………………………………………….. …………………………………………..
17. Is the community caregiver aware of your culture, family values and norms?	1. Yes [ ] 2. No [ ]
17.1 If yes, who made him/her aware?	…………………………………………… …………………………………………… ……………………………………………
18. According to your understanding, does the community caregiver respect your culture, values and norms?	1. Yes [ ] 2. No [ ]
18.1 If no, please explain why?	…………………………………………… ……………………………………………

19. Do you think the neighbors/community associate the community caregiver with HIV and AIDS?	1. Yes [ ] 2. No [ ]
20. Do you think the assistance of the community caregiver in your family contribute to neighbors/community stigmatizing your family?	1. Yes [ ] 2. No [ ] (Please substantiate your answer below) …………………………………………… …………………………………………… ……………………………………………
21. Are you satisfied with the caregiver's conduct?	1. Yes [ ] 2. No [ ] (Please substantiate your answer below) …………………………………………… …………………………………………… ……………………………………………and your recommendations are…………………... …………………………………………….. ……………………………………………..
22. Do you think your ill family member accepts the community caregiver?	1. Yes [ ] 2. No [ ] (Please substantiate your answer below) ……………………………………………. …………………………………………….

THANK YOU FOR YOUR PARTICIPATION