

**HIV/AIDS CLIENTS AND THEIR CAREGIVERS' PERCEPTIONS OF  
A COMMUNITY HOME-BASED CARE SUPPORT PROGRAMME IN  
BOTSWANA: A QUALITATIVE STUDY.**

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 .....Date: ..... 14/07/2023

## DEDICATION

I would like to dedicate this thesis to the Almighty. It is through His Love and Guidance that I managed to complete the thesis. I would also like to dedicate the thesis to my late parents for their efforts to educate me with the little resources they had. May their souls rest in peace.

University of Cape Town

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## ABSTRACT

The study was undertaken at a village called Ramotswa in Botswana. Botswana is a small country in Southern Africa with a population of 1.7 million people (Botswana Housing and Population Census, 2001).

The study explores HIV/AIDS clients' and caregivers' perceptions of the Community Home-Based Care support programme. The people involved in the community home-based care programme included nurses, family welfare educators (FWEs), social workers, community volunteers, and drivers.

An exploratory qualitative design was used. Collection of data was through in-depth interviews, as well as a focus-group discussion. The sample was obtained through purposeful sampling, and there were nine HIV/AIDS clients, and seven caregivers who participated in the study. Results of the study were analysed thematically.

Results showed that many caregivers are women, and that they perform the task of care-giving under very difficult situations of poverty, social isolation, fear and stigma. They needed financial, material, spiritual, as well as professional support from the home-based care team and community members.

The study is of particular relevance in that it was able to identify problems faced by people living with HIV/AIDS (PLWHA) receiving home-based care and their caregivers. The outcome of the study may well assist in the planning and design of a better programme to be able to provide quality care and support services to future HIV/AIDS home-based care clients and their caregivers.

## LIST OF ACRONYMS

1. ACHAP	African Comprehensive HIV/AIDS Partnership
2. AIDS	Acquired Immune-Deficiency Syndrome
3. ARV	Anti-Retroviral
4. BOTUSA	Botswana-USA Partnership
5. CBO	Community Based Organization
6. CHBC	Community Home-Based Care
7. DRP	Drought Relief Programme
8. FBO	Faith Based Organization
9. FWE	Family Welfare Educator
10. HIV	Human Immune-deficiency Virus
11. MOH	Ministry of Health
12. MTP	Medium-Term Plan
13. NACA	National AIDS Coordinating Agency
14. NACP	National AIDS Control Programme
15. NGO	Non-Governmental Organisation
16. PLWHA	People Living With HIV/AIDS
17. PMTCT	Prevention of Mother-to-Child Transmission (programme)
18. SADC	Southern African Development Community
19. SEDC	South East District Council
20. STD	Sexually Transmitted Diseases
21. UNAIDS	United Nations Programme on HIV/AIDS
22. UCT	University of Cape Town
23. UNDP	United Nations Development Programme
24. WHO	World Health Organisation

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# CHAPTER ONE

## INTRODUCTION

Located in the central portion of Southern Africa, Botswana is a sparsely populated country with an area of 582,000 square kilometres, and a population of 1.7 million (Botswana Housing and Population Census, 2001). The population distribution presents challenges for the provision of social amenities, including health care services, because of the way the population is scattered all over the country. Furthermore, the lack of adequate resources, especially human resources and poor road infrastructure, makes it difficult to reach remote populations to provide the necessary health care and social services.

There are a variety of health services in Botswana, those owned and administered wholly by the government, and those owned by private companies and individual practitioners. All health service providers operate under the country's public health rules and regulations. The Ministry of Health (MOH) administers government hospitals, and the Local Government Ministry administers all the clinics, health posts and mobile stops.

The present health structures (hospital and clinics) are inadequate to serve each Botswana citizen owing to the HIV/AIDS epidemic, which has exacerbated the problems faced by the health sector. These health sectors have been severely affected to the extent of being unable to cope with the demand of providing quality care to patients, hence the concept of home-based care (Botswana Baseline Study, 2001).

## **1.1 AIDS epidemic in Botswana**

Since Botswana's first HIV/AIDS case was reported in 1985 (WHO/UNAIDS, 2005), the number of AIDS clients has increased at an alarming rate. The HIV/AIDS increase is accounted for by the observation that Botswana has one of the most mobile populations in the world, with people migrating between cattle posts, land areas, main villages, towns and South African mines and farms. Migration movement is a general factor in the dynamics of the co-evolving epidemics of tuberculosis, HIV/AIDS and sexually transmitted infections (UNAIDS, 2005). Because of the HIV pandemic, opportunistic infections like tuberculosis gradually increase at an alarming rate from a single to a more complicated form, and the two usually occur simultaneously.

Life expectancy at birth thus fell from 65 years in 1990-1995 to 39.7 years in 2000-2005, a figure about 21 years lower than it would have been without AIDS (WHO/UNAIDS, 2004a). In 2003, there were around 160,000 orphaned children living in Botswana, more than three quarters of whom had lost a parent to AIDS (WHO/UNAIDS, 2004a). According to the WHO/UNAIDS (2004a) report, the country has the second highest HIV prevalence in sub-Saharan Africa after Swaziland. The HIV virus is most prevalent among Botswana citizens aged 25-34 years. Young women are at a higher risk for HIV infection than their male counterparts at 9.8% to 3.1% respectively (WHO/UNAIDS, 2004c).

Out of an overall population of less than 2 million in 2004, there were an estimated number of 260,000 people living with HIV/AIDS in Botswana, which gives the country a prevalence rate of 36.5% among pregnant women (WHO/UNAIDS, 2004a).

## 1.2 Home-based care

The growing numbers of HIV/AIDS patients in Botswana has placed tremendous pressure on hospitals and other facilities in the health system. This pressure has come in the form of congestion in the hospitals, which, accompanied by staff-shortage has placed a strain on the part of hospitals in giving quality care to patients. The growing number of HIV/AIDS patients and, by extension, the need to care for the terminally-ill has created a demand for health services beyond that which the existing facilities can provide. The effects of the epidemic thus produced a process of establishing a home-based care programme for HIV/AIDS and other terminally-ill patients, which was officially launched countrywide in 1999.

A baseline study for the Community Home-Based Care (CHBC) programme for terminally-ill HIV/AIDS patients in Botswana, which was conducted by the AIDS/STD Unit of the Ministry of Health, had indicated that the costly nature of the formal health system, coupled with the accelerating increase in HIV/AIDS cases, had made it impossible for the country's health infrastructure to cope with the demand (Botswana Baseline Study, 2001). The existing health facilities therefore experienced serious overcrowding of patients with the limited staff being unable to perform all their daily activities. All these problems had prompted the government of Botswana to establish the home-based care programme.

Community home-based care has been defined as the care given to an individual in his/her own environment (home), by his/her family and supported by skilled welfare officers and the community to meet not only the physical and health needs, but also the spiritual, material and psycho-social needs (Gaborone Declaration on CHBC, 2001). The home-based care programme aims at:

- Ensuring optimum level of care for terminally-ill patients in order to avoid the “dumping syndrome”;
- Avoiding unnecessary hospital admissions;
- Providing clinical care in the home, including the administration of medications;
- Providing on-going counselling services to both people living with AIDS and their families;
- Referring terminally-ill patients to social welfare and other appropriate agencies for material support; and
- Establishing functional referral systems between the hospitals, district teams and clinics.

Proper functional referral systems ensures continuum of quality care. An effective and functioning referral system ensures that chronically ill patients continue to receive appropriate services after discharge from health care facilities within their respective communities and homes and revert back to facility care as and when needed ( MOH, 2005). In sub-Saharan Africa, the referral system in districts has four levels that can be utilized. These include (1) the community, (ii) the dispensary, (iii) the health centre, and (iv) the district hospital. Patients are referred through these levels in an ascending order and vice-versa. Referral of home-based care clients/patients will depend on his/her needs and the support system in a particular community.

In Botswana the home-based care programme is coordinated at two levels: the national and the district level. At the national level, the national coordinator oversees the programme’s run at district level. At district level, the coordinator reports to the

national coordinator and is assisted by retired nurses, social welfare officers, family welfare educators, and trained community volunteers for the daily routine programme of home-based care clients which covers the following activities; daily counselling, bathing, providing treatment, cleaning of the yard and house, doing the laundry, assessment for eligibility of the food basket, training of caregivers, supply of protective materials like mattresses and wheelchairs and hand gloves, exercising their limbs, and feed those who can't feed themselves. These daily routine activities are performed at home and at the Siga home-based care centre, which will be the focus of the study.

### **1.3 Role of community volunteers**

The community volunteers at the time of the study were twenty in number. Community volunteers assist in bathing the clients; preparing simple meals for the clients; massaging the clients; and reminding the clients to attend medical check-ups and to regularly take their medications. Community volunteers are expected to observe and report any change in the client's condition to the home-based care team for further assessment.

Community volunteers are also involved in income-generating activities (such as gardening, poultry farming and sewing) to assist those who are financially disadvantaged in sustaining themselves. Each volunteer spends a day at the centre with the clients, providing care and support. Once they have been brought to the centre, the clients are provided with food and spiritual and emotional support. The support is given daily and is coupled with health education and other life-skills training before they are taken back to their respective homes at the end of the day. The rest of the volunteers are supposed to visit other terminally-ill patients in their respective homes in order to provide care and support.

## **1.4 Need for intervention**

The high HIV prevalence rate prompted the government of Botswana to initiate different forms of intervention. Their response to the AIDS epidemic, therefore, has been divided into three periods. The first period (1987-1989), focused mainly on the screening of blood to eliminate the risk of HIV/AIDS transmission through blood transfusion. The second period (1989-1997), promulgated in the first Medium-Term Plan (MTP), saw the introduction of the information, education and communication programme, but the response was quite narrowly focused (Botswana Cabinet, 1993). The third period (1997 to date) witnessed a response to HIV/AIDS which was expanded in many different directions to include: public education and awareness; the education of youth; and condom distribution and education. The third period saw the further targeting of highly mobile populations (truck drivers in particular), and a move to other areas such as the prevention of mother to child transmission (PMTCT) of HIV/AIDS, and further prevention and comprehensive care through the provision of antiretroviral treatment ( Botswana Cabinet, 1993: Botswana HIV/AIDS Second MTP, 1997). Botswana was thus one of the first African countries to provide antiretroviral therapy.

Outside state initiatives in the fight against HIV/AIDS, civil society through non-governmental organisations (NGOs) have complemented government efforts through their own programmes. NGOs such as the African Comprehensive HIV/AIDS Partnership (ACHAP) and the Botswana-United States of America (BOTUSA) partnership have the most high profile anti-AIDS initiatives in Botswana alongside

governmental programmes. The NGO's programmes aimed at supporting the goals of the Botswana government in decreasing HIV incidence in the country.

## **1.5 Gender Distribution**

Sub-Saharan Africa remains the worst affected region in the world. UNAIDS estimates that some two million people died of AIDS in the region in 2005, compared to approximately 1.9 million in 2003. The number of people living with HIV increased from an estimated 23.5 million to an estimated 24.5 million in 2005 (UNAIDS 2006). Three quarters of all women (15 years and older) living with HIV are in sub-Saharan Africa. Women are disproportionately affected by AIDS compared to men, expressions of the often highly unequal social and socio-economic status of women and men (UNAIDS, 2006). Women comprise an estimated 13.2 million or 59% of adults living with HIV in Africa south of the Sahara (WHO/UNAIDS, 2006). According to the HIV/AIDS Epidemic Report of 2005, Botswana contained 190,000 women with HIV/AIDS in 2003 aged between 15-49 years with a prevalence rate among pregnant women of the same age at 37.4 % ( WHO/UNAIDS, 2006). The tendency for women to occupy low social and economic positions, combined with greater biological susceptibility to HIV, placed them at an increased risk of infection. In a predominantly patriarchal society, women have little or no voice in making decisions around sexual practices. It follows that this tendency exposes women to unsafe sexual encounters (Langen 2005), thereby fuelling the spread of HIV/AIDS. Furthermore, deteriorating economic conditions make it difficult for women to regularly access health and social services. This entrenches their vulnerability and susceptibility to the HIV/AIDS epidemic. Thus gender inequalities are a major driving force behind the AIDS pandemic in Botswana.

## **1.6 Objectives of the Study**

### **Main Objective**

To explore the perceptions among HIV/AIDS clients and their caregivers about the social support structures available to them while receiving home-based care.

### **Specific Objectives**

1. To document/assess support available to HIV clients and their caregivers.
2. To assess referrals of patients at various levels of care;
3. To identify and describe experiences of PLWHA and their caregivers;
4. To address issues on the burden of HIV/AIDS support and care; and
5. To make recommendations to government and non-governmental organizations concerning the home-based care package for HIV/AIDS clients and those caring for them.

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# CHAPTER TWO

## LITERATURE REVIEW

### 2.1 Introduction

This section will review literature related to HIV/AIDS clients and their caregivers' perception of social support system while receiving home-based care.

### 2.2 Global and regional HIV/AIDS situation

HIV/AIDS is a major problem worldwide. According to the HIV/AIDS Epidemic Report Update (2005) statistics showed that there were 38 million adults aged 15-49 years living with HIV/AIDS worldwide. There were also over 4.9 million new infections in the same year. Of the 38 million adults living with HIV/AIDS in 2005, 17.5 million were women aged between 15-49 years. From the time the first AIDS case was observed in Africa, the HIV/AIDS epidemic has spread throughout the continent with devastating effect. By the end of 2001, there were an estimated 28 million adults and children living with HIV/AIDS in sub-Saharan Africa (Piot et al, 2004). The region continues to bear the brunt of the pandemic, as more than 25 million adults and children live with HIV/AIDS, many of whom live in Southern Africa, where the prevalence rates are extremely high (Mokili and Korber 2005). According to the HIV/AIDS Epidemic Report Update of December 2005, an estimated 3.2 million people in the region became newly infected, while 2.4 million adults and children died of AIDS. The report further revealed that, among young people aged 15-24 years, an estimated 4.6% of women and 1.7% of men were living with HIV.

With regard to gender and HIV/AIDS, women are probably more susceptible than men to infection from HIV in any given sexual encounter, owing to biological factors (WHO/UNAIDS, 2006). Gender norms may also have an impact on HIV transmission. In many places, for example, gender norms allow men to have more sexual partners than women, and encourage older men to have sexual relations with much younger women (WHO/UNAIDS, 2006). In combination with the known biological factors, this means that, in most places where heterosexual sex is the main mode of HIV transmission, infection rates are much higher among young women than among young men (WHO/UNAIDS, 2006).

Progress in advancing treatment and care provision in sub-Saharan Africa has been uneven. Botswana and Uganda were the only countries providing antiretroviral therapy to at least one third of their citizens. Other countries only started providing ARV in mid 2005 (UNAIDS/WHO, 2005).

### **2.2.1 Botswana's HIV/AIDS overview**

According to the HIV/AIDS Epidemic Report Update (2005) Botswana's epidemic appears to be stabilizing, but at extra-ordinary high levels, with National HIV prevalence among pregnant women having remained between 35% and 37% since 2001. Infection levels among older women and men were unexpectedly high: 29% for those 45-49 years old and 21% for those in their early 50s (HIV/AIDS Epidemic Report Update, 2005).

In 2003, there were 23.1 million adults between the ages 15-49 years living with HIV/AIDS, and out of this total, 13.5 million were women of the same age group. Those

with new infections in 2005 were 3.2 million with deaths from HIV/AIDS totalling 2.4 million in 2005 (WHO, 2005). Globally, there is evidence that adult HIV- infection rates have decreased in certain countries. This decline in infection rates has been attributed to changes in behavioural sexual practices that saw the increase in the use of condoms, the delay of first sexual experience, and fewer sexual partners (WHO/UNAIDS, 2004b). Despite decreases in the rate of infection in certain countries, the overall number of people living with HIV has continued to rise in all regions of the world except the Caribbean (WHO/UNAIDS, 2004b).

### **2.3 Community Home-Based Care**

As a result of the epidemic world-wide, countries such as Zambia, South Africa, Uganda, Kenya and Botswana in sub-Saharan Africa, and other European countries, resorted to the concept of Community Home-Based Care. Existing health facilities in resource-poor countries remained inadequate even for the delivery of basic health care (WHO, 2002a). Many health care facilities reported a dramatic rise of 70% to 80% in bed occupancy for persons with HIV-related conditions (WHO, 2002a). In addition, health care workers, like the rest of the population they serve, often succumb to HIV infection and AIDS. The HIV pandemic continues to gather momentum in many developing countries, increasing the already heavy burden placed on health care facilities (Mc Donnell et al, 1994). More recently, many African countries have also been experiencing an exodus of nurses to overseas countries, exacerbating the situation in those countries worst hit by the epidemic.

The concept of home-based care is not new. In the past it was used for the care of the elderly and of individuals with chronic diseases (WHO, 2002b). Community Home-

Based Care (CHBC) has been defined as any form of care given to ill people in their homes. Such care includes physical, psychological, palliative and spiritual activities. The programme's goal has been to provide hope through high-quality and appropriate care, which helps ill people and their families to maintain their independence and achieve the best possible quality of life (Hirschfeld et al, 2002). The effectiveness of the programme depends mainly on seven essential elements:

- Provision of care;
- Continuum of care;
- Education;
- The adequate provision of supplies and equipment;
- Staffing;
- Financing and sustainability; and
- Adequate monitoring and evaluation.

Taken together, these provide a sufficient and holistic home-based care programme (Hirschfeld 2000).

The literature suggests that home-care programmes for people living with HIV/AIDS were mainly initiated in North America and Europe in the late 1980s (Spier and Edwards 1990). In the United States, the Committee on a National Strategy for AIDS (1996) resolved that, if the care for PLWHA was to be comprehensive and cost-effective, it must be conducted as much as possible within the community, with hospitalization only when necessary.

In sub-Saharan Africa and in other developing countries, community home-based care programmes were developed as unsystematic and needs-based efforts when it became

evident that other options of care were necessary to deal with the effects of HIV/AIDS (WHO, 2002a). Different organizations such as non-governmental organizations (NGOs), community-based organizations (CBOs), faith-based organizations (FBOs), and concerned individuals, initiated the programmes (Cullinan 2000).

In Botswana, the CHBC programme started in 1994, but was officially launched in 1999. The CHBC programme is guided by the National HIV/AIDS policy that was reviewed in 1998 to incorporate home-based care, and the National HIV/AIDS Strategic Plan (Medium-Term Plan 11) that was developed in 1997 (Gaborone Declaration on CHBC, 2001). The development and administration of the programme is the responsibility of the Government with some assistance from business and community-based organizations. Botswana is no different from other developing countries. With its limited resources, not all people in need can be included in the proposed CHBC services, given that the care is supposed to include emotional support, spiritual support, personal care, counselling and education in the area of HIV/AIDS, and home-based care. The programme gives the family members all the responsibility of care, but they still need outside support to be able to cope with the demands of care.

Extensive research has demonstrated the profound negative effect of chronic illness on families (McMillan 1996; Payne, Smith, and Dean 1999; Pearlin, Aneshansel, and LeBlanc 1997). The majority of personal care provided to terminally-ill patients continues to be given by family members and friends (Emanuel et al, 1999) and as a direct result of the stress and strain of care-giving, these caregivers themselves tend to develop illnesses such as hypertension and their own health often also deteriorates into chronic disease over time.

## **2.4 Physical and psychological health in family care-giving**

In 2004, Stetz and Brown conducted a study on physical and psychological health in family care-giving in which they compared AIDS and cancer caregivers. The purpose of the study was to compare cancer and AIDS family caregivers with regard to their physical and emotional health and it found that both AIDS and cancer caregivers reported high levels of stress and depression as compared to community norms. The groups differed on several individual subscales. In the context of these findings, it is clear that caregivers of terminally-ill patients experience stress and depression and therefore need regular external support. The absence of any such support will tend to hasten the development of certain ailments among the caregivers, resulting in the provision of sub-standard care. It follows that caregivers themselves need external support to serve as a barrier towards the development of negative physical and psychological health effects, which might interfere in turn with the caring process of PLWHA.

## **2.5 Knowledge of HIV**

Mbata-Ndaba and Seloilwe (2000) conducted a study that assessed the knowledge and perceptions of caregivers of terminally-ill patients receiving home-based care in Botswana. Their findings indicated that many families lacked the knowledge and skills necessary for providing appropriate care. Lack of knowledge and skill interfered with the provision of quality care to PLWHA. The study recommended that a sound follow-up system needed to be in place for the effective implementation of home-based care, with equally appropriate procedures for monitoring and evaluation. This observation is supported by other research literature, which indicates that families who receive

detailed information about the condition of the patient manifest more vigilant coping skills, compared with families who receive little or information of only a general variety (LaMontague 1987). Furthermore, there are clear and beneficial effects to be obtained from well-run home-care preparation programmes, such as the reduction of family distress and anxiety usually associated with caring for terminally-ill individuals. Well-informed and trained families are often less anxious and ready to receive and give quality care to a family member suffering from a terminal condition. The literature has also shown that access to preparatory information, continued training, and active support from health workers is vital for psychological coping and the provision of quality care among home-care providers (Lindsey et al, 2003; Thoits 1995). Individual experiences of ill health are often shared within a self-help group, which may then act as a repository of knowledge about a particular ailment or experience and that collective knowledge may then be used both for the benefit of other members and for the rest of society (Stajduhar 1997). The literature further states that self-help groups can bring many other benefits to members, such as the sharing of advice on lifestyles or coping strategies, or acting as a refuge for isolated individuals, especially those suffering from the social stigma of HIV/AIDS (Stajduhar 1997).

The provision of knowledge about HIV/AIDS is another form of social support to both PLWHA and their caregivers. A study by Mbata-Ndaba (1998) shows the importance of providing education to caregivers of terminally-ill patients since lack of knowledge can put them at danger of contracting the virus if they do not take the necessary precautions. With the skill and knowledge thus acquired, they might also provide the care in the full knowledge of what to expect with regard to frequent changes in the patient's condition; mood swings; where to ask for assistance; and where to find the

material resources such as hand gloves to aid in the provision of safe quality care. Same results were yielded by a study by the same authors (Mbata-Ndaba and Seloilwe 2000) this time assessing knowledge and perceptions among caregivers of terminally ill patients on home-based care in Botswana. The results showed knowledge deficit as a common factor among caregivers in the home despite the efforts initiated to disseminate information on home-care.

Quite a few studies have been conducted in Botswana and elsewhere, which have sought to assess knowledge of HIV among those caring for PLWHA (Lamontague 1987; Mbata-Ndaba and Seloilwe 2000; Stajduhar 1997; Thoits 1995; Watson 1985). The findings of these studies confirmed the present study's hypothesis that caregivers of PLWHA are not always equipped with the necessary skill and knowledge to help them execute their duties effectively as they care for their clients on a home-based care programme.

Maneesriwongul et al, (2004) conducted a study in Thailand, which assessed the educational needs and support available to family caregivers of persons living with HIV/AIDS. This was a qualitative study, which aimed at learning more about the need for education and active support for family caregivers of HIV-positive clients on a home-based care programme. The major themes identified were: fear, stigma, sorrow, empathy, hopelessness, and hope. In addition, participants voiced the need for education to improve their knowledge and skills related to the care of PLWHA. These findings showed a widespread knowledge deficit among family caregivers of PLWHA.

## 2.6 Caring

According to Watson (1985) cited in Kabuluzi (2005) caring is the moral ideal of nursing whereby the goals are protection, enhancement, and preservation of human dignity. Some of the considerations brought to the fore by Watson are that caring entails the promotion of interpersonal teaching and learning; and the provision of a supportive, protective and corrective mental, physical, socio-cultural and spiritual environment.

Caring for PLWHA involves both religious and spiritual care. In a study by Siegel and Scrimshaw (2002) which investigated the perceived benefits of religious and spiritual coping among older adults living with HIV/AIDS, a variety of benefits were reported. They affirmed that spiritual beliefs and practices offer strength, empowerment and control; ease the emotional burden of the illness; and offer social support and a sense of belonging. They also suggested that such beliefs and practices offered spiritual support through a personal relationship with God, facilitating meaning and the acceptance of illness, while relieving the fear and uncertainty of death.

These studies informed this current study in that they demonstrated that terminally-ill persons and people involved in providing care undergo a lot of stress, frustration and anxiety, and as such need all the aspects of caring stated above in order to be strong, and be able to be in a position to accept their conditions; while caregivers need the support to provide quality care and to be able to develop a helpful and trusting relationship with a full set of coping strategies.

Caring as defined by Watson (1985) is a complex issue, and to be in a position to provide quality care, caregivers have to be in a healthy physical and mental state, and can only be in that position if they are provided with active support, which in most cases is lacking. Other studies have been conducted on home-based care and HIV/AIDS as reflected in the literature, but nowhere does it show that PLWHA and their caregivers receive sufficient support that is relevant to their needs, a factor which needs to be considered in any home-based care programme.

## **2.7 Challenges and strategies**

Shaibu (2006) in a study on community home-based care in a rural village in Botswana explored the challenges faced in the implementation of home-based care programmes. Home-based care-giving drained families of their limited resources, resulting in poverty. Poverty as a whole needs to be addressed, especially in Botswana, where HIV/AIDS prevalence is high with people already on antiretroviral therapy (ARVs) but do not receive active support from either community members or non-governmental and community-based organisations. This means that HIV/AIDS clients receiving home-based care and their caregivers need continuous support in the form of food rations, for example, to boost their immune systems and grants-in-aid in order to purchase those material goods required for adequate care and which are not provided by the programme.

## **2.8 Caregivers' experience of informal support**

In 2002, D'Cruz conducted a study in Mumbai, India that looked at caregivers' experiences of informal support in the context of HIV/AIDS. According to the study, social support is an important buffer for family caregivers of PLWHA. Social support

is considered to be positively related to good health, better health outcomes, better coping and less negative effects of stress. For people caring for PLWHA, a comprehensive support system is needed to reduce stress, depression and hopelessness, one, which is able to actively help the needy with community assistance. The caregiving literature continues to emphasize the critical importance of social support for all groups of caregivers in maintaining health and well-being (Brown and Powell-Cope 1991; Kelly et al, 1996; Powell-Cope 1994; Stajduhar 1997).

According to the results of the study by D'Cruz (2002) support is necessary because it acts as a buffer to the development of stress, depression, anxiety, hopelessness, and fear, which might otherwise interfere with the maintenance of good health and well-being in both HIV/AIDS clients and their caregivers.

## **2.9 Socio-economic characteristics**

Katapa (2004) conducted a study in Tanzania, which looked at the socio-economic characteristics of caretakers of HIV/AIDS patients receiving home-based care. Results showed that the caretakers lacked the basic means to support their patients; that community members offered very little or no support to caretakers; and that those households were stigmatised. A further study by Lindsey et al (2003) also produced the same results as Katapa's that HIV/AIDS caregivers lacked the basic means and were stigmatised.

In another study by Fako and Gary Linn (2006) investigating social and economic stress related to the HIV/AIDS epidemic in Botswana, the findings revealed that, in addition to frequently experienced trauma due to sickness and death, many households

experienced rising health expenditures and a sharp deterioration of incomes. Results further revealed that the stigma usually associated with AIDS often isolates fragile households and provides an environment in which abuse of the infected can go undetected. Study findings revealed that an increase in morbidity due to HIV and AIDS would weaken and kill able-bodied working persons who support countless dependent children, the elderly, and grandparents. The advent of HIV and AIDS also result in the reduced availability of household labour. People mostly affected by the HIV/AIDS pandemic are the working class, the reason for reduced labour. There is also reduced educational and employment opportunities for children from affected households as some leave school to care for their brothers and sisters following the death of a parent from HIV/AIDS (United Nations Development Programme, 2000).

Molatole (1998) conducted a study in Botswana exploring the social support resources available to AIDS patients and their family members within community home-based care programmes. The findings indicated that people lacked financial support to be in a position to effectively care for their patients, and that this lack of finance may have had a negative impact on the health outcomes of the clients and their caregivers. The results also showed that AIDS clients and their caregivers were receiving minimal material and emotional support from the designated health-care providers. In addition, health care professionals provided informational support. Study participants saw the informational support provided as more relevant to prevention of HIV/AIDS than to the care of an already infected sick individual (Mathebula 2000). Financial support is important for PLWHA because they are already on antiretroviral treatment and the therapy alone would not be effective without proper diet for the repair of worn-out tissues. HIV/AIDS and poverty are common factors in PLWHA, and therefore need to

be addressed decisively for the effective implementation of a home-based care programme, thereby reducing unnecessary hospitalizations (Fako and Gary Linn 2006; Lindsey et al, 2003; Mathebula 2000; Orner 2005).

The above studies have clearly indicated how important active support is to PLWHA and their caregivers. People must come forward to support PLWHA and their caregivers to make home-based care an efficient and effective programme.

## **2.10 Psychological impacts on caregivers**

Orner (2005) conducted a study entitled: “The psychological impacts on caregivers of PLWHA: A qualitative study to determine gender, programme, and policy implications”. The study was conducted at Khayelitsha, Gugulethu and Delft. Some of the objectives of the study were: to describe the type of support caregivers received; what they found most useful; and what kinds of support they would like. The results of this study indicated that the care-giving process placed considerable demands on caregivers, negatively impacting on their mental-health status. This was exacerbated by insufficient support, and the dire poverty experienced by most respondents. The results went on to state that a lack of basic resources was common and chronic, and that the caring process impinged on employment and social life. Overall care-giving tended to impoverish life both emotionally and materially (Orner 2005) hence the need for active support. The results of the study indicated clearly that there are a lot of problems in home care-giving, and that these problems could only be avoided or reduced by providing active support to people caring for HIV/AIDS clients.

A related study by Simeza (2002) cited in Kabuluzi (2005) exploring nursing students’ perceptions and experiences of caring for HIV/AIDS in Malawi, revealed that the

students' experience of providing care was challenging because of their limited knowledge, and unexpected personal and patient responses. Their experience was characterised by an intense fear of being infected and the threat of social stigma. Simeza's study has resonance in that whilst they were professionals, they too experienced challenges in caring for HIV/AIDS patients and as such both need the necessary knowledge and skill on how best to care for an HIV/AIDS patient. In this way, they would not experience a lot of stress as a result of unexpected patient responses, fear of contracting the AIDS virus because they would apply more appropriate preventive measures when caring for the sick.

Chesney and Smith (1999) and Goldin (1994) cited in Plattner and Meiring (2006) conducted a study entitled "living with AIDS: The psychological meaning making". The results of the study revealed that the inevitable confrontation with death, sooner or later, and the stigma attached to the virus, made HIV/AIDS one of the most feared of all diseases. Living with AIDS means having to cope with a combination of various kinds of psychological challenges caused by multiple losses, fears and anxieties, uncertainties, feelings of shame, guilt, self-blame, and social stigmatization, and therefore the need for support. Being HIV-positive may mean the loss of health, friends, employment, and financial independence (Dansky 1994; Friedland et al, 1996; cited in Plattner and Meiring 2006).

Silverman (1993) in his study on HIV/AIDS found that occupational stress and burnout contributed to the poor quality of work in the care of PLWHA. Caregivers of PLWHA commonly reported symptoms of chronic work stress such as physical exhaustion and headaches (Silverman 1993; cited in Kabuluzi 2005).

Studies conducted on HIV/AIDS, fear and burnout (Chesney and Smith 1999; Goldin 1994; Simeza 2002; Silverman 1993) indicated clearly that caregivers of PLWHA experience fear, stress, social stigma, and burnout. With these multiple problems, HIV/AIDS clients and their caregivers need psychological and social support to help them overcome some of these problems. These represent only a few of the studies conducted to help improve the implementation of home-based care, especially in the area of social support.

A study by Lindsey et al (2003) conducted in Botswana, explored the impact of care-giving on young girls and older women caring for family members living with HIV/AIDS and other chronic and terminal illnesses at home. Respondents - especially older women - reported feeling overwhelmed with the magnitude and multiplicity of tasks they had to perform. They reported feeling exhausted, malnourished, depressed, and often neglectful of their own health. In addition, caregivers experienced poverty, social isolation, stigma, and a lack of care-giving education. The study results support what most respondents complained about in the current study being undertaken: that caregivers do experience difficulties in their caring work, and therefore must be supported physically, mentally, spiritually, emotionally and materially. Experiences such as depression, fatigue, and social isolation, if not taken seriously, could predispose caregivers to a range of illnesses. For caregivers to be able to cope effectively, they need a supportive-caring environment.

Reynolds and Alonzo (1998) conducted a study on HIV informal care-giving to a family member or partner with HIV. The results suggested the need for providing

formal care to HIV/AIDS patients which will involve other sectors that could play an important role in the care-giving process, thus serving to lessen the conflicting and psychological process which can often interfere with the provision of quality care.

## **2.11 HIV/AIDS care and support**

Russell and Schneider (2000) did a rapid appraisal of community-based HIV/AIDS care and support in South Africa. HIV/AIDS community-based care and support was defined as being all HIV/AIDS activities that are based outside conventional health services such as support groups (Russell and Schneider 2000). The overall experience of PLWHA appeared to be one of deepening poverty; isolation; an inability to satisfy basic needs such as food and shelter; rejection by the community and the formal sectors; and fear for their children.

The establishment of HIV/AIDS support groups was seen as essential by PLWHA. PLWHA felt that support groups would add a new chapter to their lives because they would be able to interact with others; would realize that they are not the only people suffering; and also realize that there are other people out there with the same disease whom they could talk to (Russell and Schneider 2000). They believed that being alone and thinking about the disease was stressful. A support group was seen as being able to help people learn and become more tolerant and accepting of HIV/AIDS (Russell and Schneider 2000). Support for PLWHA was found to be “patchy” and most of the time to be lacking. Without support, they observed, life becomes difficult for PLWHA and their caregivers (Russell and Schneider 2000). Russell and Schneider (2000) inform the present study in that it supports the contention that PLWHA and their caregivers need social support to be able to cope with the stressful situation of living with HIV/AIDS,

and of having to face the harsh realities of the disease and its prolonged deterioration of health.

Studies have been conducted in Botswana on issues of HIV/AIDS and home-based care, but none so far has investigated the perceptions of HIV-positive clients and their caregivers of a community home-based care programme. No studies have been conducted to investigate how HIV-positive clients and their caregivers feel about the support they receive while receiving home-based care. This current study aims therefore to close the existing knowledge gap. Some of the studies conducted on HIV/AIDS and home-based care have been discussed above, but their focus was not on social support structures.

## **2.12 Giving care to people with symptoms of AIDS**

Chimwaza and Watkins (2004) conducted a study entitled “Giving care to people with symptoms of AIDS in rural sub-Saharan Africa”. Caring for those with AIDS is assumed to be a substantial burden, but little is known from the perspectives of those who actually provide the care; hence the study. The study focused on among other things the type and duration of care they provided, the support they received from relatives and other members of the community, and the extent by which care-giving was experienced as an emotional, physical and financial burden. The study results showed that care-giving was given by close female relatives of the patient. Caregivers showed compassion and made attempts to provide the best care possible in their circumstances. Members of the community provided social, moral, and physical support, as well as modest financial assistance. The study further revealed that care-giving was physically and emotionally demanding and confined the caregivers to their homes, but most caregivers didn’t consider care-giving a problem primarily because the

patients were close relatives. The study informs the current study in that caregivers of terminally ill individuals need support to cope with the demands of caring.

### **2.13 Effective home-based care**

In 2004, Campbell and Foulis conducted a study focusing on creating contexts for effective home-based care of PLWHA as little was known about how to facilitate contexts that would maximize the effectiveness of carers. The study findings identified multi-level factors that undermine carers in performing their role. Such factors include lack of knowledge, skills and support both at the individual and organisational level; physical and psychological burnout; the destruction of household economies in the face of the demands of care; community stigma and rejection. The study ended up by recommending the concepts of bonding, bridging and linking social capital within a framework sensitive to the interaction between poverty as a starting point for the development of better understanding of the types of networks and partnerships most likely to support carers and their local committees ( Campbell and Foulis 2004). The study shows how important it is to have a clear support and network system if countries want to see a smooth running of programmes to help those in need of care and support.

### **2.14 Gendered consequences of care-giving**

Like the rest of the African countries, South African is promoting home-based care programme due to the over-stretching of formal health facilities and the potential positive benefits for PLWHAs. According to Akintola (2004) little is known about the consequences of the caregivers when providing the care. The study aimed to understand and describe the gendered consequences on informal caregivers. Study results revealed that most caregivers were unmarried women, heads of families and breadwinners. Majority of the caregivers were siblings and mothers of PLWHA. Caregivers provided multiple tasks such as assistance with feeding; bathing; cleaning; washing soiled linen;

fetching drugs and liaising with medical health personnel. The tasks already affected their physical and emotional health while denying them the opportunities to engage in economically productive work that might enhance access to good food, quality health care and social activities that may create positive health outcomes. Findings suggest that home-based care programmes must take cognisance of the practical and potential consequences on caregivers (Akintola 2004). It is very clear that women indeed take the lead in almost everything including home care activities impacting negatively on their health, and therefore needing care and support from the government and local community members.

### **2.15 Integrated community-based home care model**

The model was implemented in South Africa. The implementation took place from 1999-2000. Respondents during the post implementation evaluation by Uys (2001) felt that the model could be replicated if functioning and informed network including all partners, and a strong management team were in place. The post evaluation implementation of the model resulted in hospitals and community-based services becoming more aware of and involved in the needs of PLWHA and felt that the model enabled them to address their needs. On a positive note, PLWHA and their carers felt supported and respected; one aspect that the current study is calling for. Lives of PLWHA and their carers are depleted because of the situation they are faced with, that is living with HIV/AIDS, and having to care for an HIV/AIDS patient for an unknown period under adverse situations of poverty, stigma and discrimination. All these call for support of these people to be able to cope well in such situations.

## **2.16 Summary of the literature review**

The literature thus far reviewed clearly indicates that HIV clients and caregivers experience many difficulties in trying to cope with the harsher aspects of HIV/AIDS. The caring process placed considerable demands on caregivers and therefore tends to impact negatively on their mental-health status. The caring process also impinges on both employment and social life, and care-giving tends to impoverish the quality of life both emotionally and materially (Orner 2005). Poverty and lack of financial support further presented major challenges in home care-giving. Issues of knowledge deficit in family care-giving were also prominent.

The surrounding community offered little or no support for both clients and caregivers. Caregivers - whether professionals or non-professionals - expressed fear, social stigma, discrimination, exhaustion, and little or no time for themselves as a result of the caring process. With all these multiple problems, HIV/AIDS clients need active support to cope with the disease, and caregivers likewise need the support to cope with the demands of the care-giving process.

## **2.17 Problem statement/Study Rationale**

In Botswana, there has been an increase in community home-based care following a shift from hospital care to home care because of the HIV/AIDS epidemic (Shaibu 2006). This shift in emphasis raises issues that present specific obstacles, which may have significant psychological impacts on caregivers (Orner 2005). Caring in most cases takes place under serious conditions of poverty. In addition to poverty, caregivers lack time for themselves as a result of caring. They are also stigmatised together with their clients, which further results in social isolation.

As one of the countries with the greatest prevalence of HIV/AIDS in sub-Saharan Africa, and having introduced antiretroviral therapy since January 2002, the people of Botswana can anticipate that there will be more AIDS clients that would need care for a longer period of time, hence the need for a viable and well implemented community home-based care programme to benefit the terminally ill in Botswana.

Many people who are currently infected with HIV have not yet developed AIDS, and this means that the worst of the epidemic is yet to come, as these HIV-infected people will ultimately develop AIDS, and would need to be actively supported. Since the burden of care rests largely on caregivers of PLWHA, these caregivers should be assisted adequately to cope with such a burden. It is important therefore that assessment of their perceptions concerning the support programme be evaluated, because this will indicate the nature of the social support that they need as well as that needed by their clients.

In Botswana reports already exist on the community home-based care programme and contain admirable recommendations as to how best to improve the programme, but little has been done to determine perceptions of people about the support programmes actually in place, hence the necessity for this study (D'Cruz 2002; Katapa 2004; Lindsey et al, 2000; Mbangwa 2002; Mbata-Ndaba 1998; Mbata-Ndaba and Seloilwe 2000; Molatole 1998; Orner 2005; Shaibu 2006; Stetz and Brown 2004; Thoits 1995).

The results of the study are intended to feed, inform and advise public policy on how best to improve the implementation of the home-based care programme in Botswana which will be of great benefit to the health care of PLWHA and their caregivers.

# CHAPTER THREE

## RESEARCH METHODOLOGY

### 3.1 Introduction

A qualitative methodology was selected as the most appropriate to obtain information on perceptions of HIV/AIDS clients and their caregivers on social support services available to them.

### 3.2 Study site

The research participants were drawn from South East District Council in a village called Ramotswa in Botswana. Ramotswa is the headquarters of South East District Council. The village has one district hospital; two council clinics; one privately owned Roman Catholic Mission clinic; and a few private practitioners. The village has an overall population of 60,623 of which 29,125 are males and 31,498 females (Botswana Housing and Population Census, 2001). South East District Council has a home-based care team comprising of the following staff: one home-based care coordinator, five retired nurses, and twelve principal family welfare educators

Ramotswa village has a centre (the Siga home-based care centre) where clients' counselling, feeding and education takes place. The centre is staffed with one retired nurse, one principal family welfare educator, one driver, and two social workers, and forty community home-based care volunteers. At the time of data collection, the centre had eighteen registered HIV/AIDS clients to accommodate for daily routines, but the enrolment tends to fluctuate owing to the death rate.

The current study was undertaken from December 2005 to September 2006, with a pilot study conducted for two days in the first week of December 2005, at the Siga community home-based care centre. Permission to conduct the study was obtained from the Chief Executive of South East District Council. Approval to conduct the study was also granted by the Research Ethics Committees: Health Sciences Faculty at the University of Cape Town and the Botswana Ministry of Health.

### **3.3 Study design**

The study was exploratory and descriptive in nature, using qualitative research methods. The study aimed at determining the perceptions of HIV/AIDS clients and their caregivers of a community home-based care support programme at a village called Ramotswa in Botswana.

### **3.4 Population, sampling and inclusion criteria**

The sample comprised nine HIV/AIDS clients and seven caregivers of PLWHA receiving home-based care services. HIV/AIDS clients and their caregivers were sampled on the understanding that they had been exposed to the issues associated with home-based care, and were therefore likely to provide detailed information about the support programme. Participants were selected through purposive sampling (Morse 1991).

#### Inclusion Criteria for PLWHA

People who participated in the study all met the inclusion criteria of being HIV-positive; having been recipients of a home-based care programme for at least six months; willing to participate in the study; able to speak either English or Setswana and residing in Ramotswa village at the time the study was conducted.

Participants who met the selection criteria and volunteered to participate in the study were then selected. The inclusion criterion consisted of male and female PLWHA, aged 18-65 years and residing in Ramotswa (Botswana) at the time of study. The age-range of 18-65 years was used because the disease is common in the same age group. The lowest age was chosen at 18 years because people at that age are considered mature enough to consent for themselves. As for the highest limit of 65 years, reports from workshops and seminars revealed that older people especially women develop AIDS at that age as a result of the caring practice they offer to their children (Lindsey et al, 2000; Tlou 1996). It was also found that they often refused to use protective devices such as gloves because they felt that such protection might indicate a lack of affection for their children (Lindsey et al, 2000; Tlou 1996). Similarly, during the early years of the HIV/AIDS epidemic in Botswana, parents often opted to care for their infected children without wearing hand gloves. The reasons for the refusal of using hand gloves appeared to be two-fold: a lack of knowledge about HIV/AIDS transmission, and deep-rooted feelings that the use of hand gloves indicated some form of discrimination against their infected children.

#### Inclusion criteria for caregivers

The caregivers were recruited on the following basis: having been a constant caregiver of an HIV positive client on home-based care; willing to participate in the study; able to speak either English or Setswana; and aged fifteen years and above.

#### Recruitment of participants

The researcher was granted permission by the Chief Executive of the Local Authority where the study was conducted. The home-based care coordinator for the area assigned the researcher a Family Welfare Educator to assist her in identifying participants.

Together with the Family Welfare Educator the researcher went through the home-based care register and identified those who were HIV positive and were visited at their homes, and those who agreed to participate were interviewed at their homes. Some interviews were conducted at the home-based care centre for those who were at the centre on different days.

### **3.5 Refusal**

Four clients declined to participate in the study probably because of the stigma attached to being labelled as an HIV/AIDS client. Others were in denial that they were HIV-positive. HIV-positive clients who refused to participate in the study claimed that a foreign body in their bodies was the reason for their illness, not the HIV virus. Those who were unwilling to participate in the study were therefore excluded. It is the opinion of the author that this did not in any way bias the study.

### **3.6 Data collection**

Qualitative research methods were used to collect data. In-depth interviews with individual HIV/AIDS clients and their caregivers were conducted. These were complemented with a focus-group discussion with the HIV/AIDS clients for purposes of data triangulation. Data was collected through the use of an interview guide designed differently for both clients and caregivers. All questions were open-ended, except those in the demographic section. The researcher undertook the research herself, with the help of a principal family welfare educator, who was assigned to accompany the researcher, but did not take any active role in the research.

Most of the interviews were conducted in Setswana, the local language of participants, and only a few in English because the respondents could not speak the local language.

This did not affect the study because the researcher is proficient in both languages. Responses were recorded on the same interview guide in the space provided, and a tape recorder was used with the participant's permission. The recorded data was transcribed and translated before it was analysed. There were four participants who did not allow interviews to be audio-taped for fear of being victimized as HIV/AIDS clients. Interviews took place at different places: The majority at home, with a few conducted at the Siga home-based care centre, hospice, and the Shelter for the Hopeful Community.

Background information on demographic data was collected. Demographic data included age, gender, occupation, religion, and monthly income. Data was also collected on the impact of living with HIV/AIDS from clients and on the impact of care-giving from the caregivers themselves. In cases where the researcher identified the need for food or for supplies such as hand-gloves, the information was passed over to the home-based care team to assist the client or caregiver.

### **3.6.1 Study instrument (See attached appendix)**

The interview guide was administered face-to-face. This was based on the assumption that the entire interview would give participants the opportunity to describe their experiences in their own words without any restrictions (Polit and Hungler 1995). All ethical issues relating to confidentiality, anonymity and privacy of all the study data were fully explained to participants. All the information/data was coded. No names were used.

Hand notes and a tape recorder were used to capture the interviews. Data and tape records were checked on a daily basis, and where necessary clarifications made. Data was transcribed verbatim and was read several times in order to understand it and retrieve meaning out of it. The same data was manually coded. This was followed by the extraction of patterns and themes.

### **3.6.2 Focus group discussion**

Focus group discussion is a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment (Kruger 1994). It can be used as the sole method to collect information before a questionnaire is administered or after a questionnaire has been administered to get deeper knowledge or understanding of a phenomenon. For this particular research, one focus group discussion was conducted after individual interviews with PLWHA. The focus group consisted of seven PLWHA: one male and six females. No focus group discussion was undertaken for caregivers as the researcher felt that their responses from the individual interviews had been adequate.

Individual PLWHA were followed at their respective homes and informed of the researcher's intention to conduct a focus group discussion. The purpose for conducting the focus group discussion was explained to participants, and seven PLWHA agreed to take part in the focus group. A day was set for the discussion, and it took place at the Siga home-based care centre, with the researcher facilitating the focus group discussion. During the focus group discussion important points were noted, and non-verbal communication was also captured. Focus group discussion together with one-to-one individual interviews improved the quality of data.

### **3.7 Pilot study**

A pilot study was conducted over two days at the Siga home-based care centre in the first week of December 2005. The pilot study was conducted to test for clarity of the instrument and to see if questions were understandable; to determine the appropriateness of the instruments; to identify and manage logistical problems; as well as establishing the average duration of the interview. The results of the pilot study were analysed and thus further helped the researcher to rephrase some of the questions so that greater understanding by the participants might better yield the information required.

### **3.8 Data analysis**

In this descriptive study, a thematic analysis of the data was conducted, using qualitative research methods (Creswell 1998). Creswell explains that data analysis involves reducing an enormous amount of information into categories and themes so that it may be interpreted (Kabuluzi 2005). Data from individual interviews and a focus-group discussion was transcribed, and read several times in order to make meaning out of the material. The initial impression that was derived from the data was recorded and coded manually. These codes were later combined to provide categories of responses. These categories were further refined and incorporated into research themes. Finally, patterns and themes that exemplified the perceptions and experiences of clients and family caregivers were identified.

### **3.9 Ethical considerations**

Every effort was made to ensure that the research complied with the ethical principles enunciated in the South African Guidelines on the Ethics Medical Research Council.

Written consent based on clear and adequate information was sought from all participants. The aim, objectives, procedure involved, duration, general scope of the study as well as the institutional affiliation of the researcher were fully disclosed to the participants in their first language prior to the signing of the consent form.

Before the start of the interviews, willing participants were asked to sign the consent form. Participants were informed of their right to abstain from participating in the study altogether and their right to withdraw consent at any time without reprisal. They were also assured of confidentiality. Anonymity was ensured by not using people's names, but instead codes were used. They were told that only aggregated data would be reported and that personal information would be destroyed when the project had reached finality.

Having discussed the methodology utilised in the study, chapter four will discuss the findings of the study as emerging from the data analysis.

# CHAPTER FOUR

## STUDY FINDINGS

### 4.1 Introduction

This section presents the results of the study on the perceptions of nine HIV/AIDS clients and seven caregivers on the social support services they receive.

### 4.2 Demographic characteristics (See attached appendix)

#### 4.2.1 HIV/AIDS clients

All study participants were aware of their HIV-positive status. The mean age for clients was 30 years. The total number interviewed was nine HIV/AIDS clients with eight females, and one male. Their ages ranged between 26-53 years. Three participants had their ages ranging between 20-29 years; four ranging between 30-39 years; one between 40-49 years; and one between 50-59 years of age. Out of nine respondents, one had primary education, six had secondary education, and two had tertiary education. With regard to employment, six out of nine respondents had to leave employment because of the morbidity due to HIV/AIDS, leaving three employed. Seven respondents were affiliated to different faith denominations such as: Roman Catholic, UCCSA, Muslim, Apostolic, Lutheran, and Assemblies of God, with two not affiliated to any denomination (See attached appendix).

#### **4.2.2 Caregivers of PLWHA**

As literature reveals, caregivers of terminally ill patients are mostly women (Bakker et al, 2006; Lindsey et al, 2000). This is consistent with the findings of the current study, where caregivers were all women, with their ages in years ranging between 41-67 and a mean age of 43 years. Three had their ages ranging between 40-49 years; three between 50-59 years; with one over 60 years of age. More than half of the caregivers attended primary education (4), one attended secondary education, with only two having attended tertiary education. Almost all the caregivers were unemployed, with the exception of one caregiver, who combined the care-giving work with her employed work. All except one caregiver belonged to different religious denominations, with four out of six attending Roman Catholic Church, one Apostolic church, and one Lutheran church. The caring period ranged between eight months to two years. Three caregivers provided care to their clients for less than a year; while four caregivers provided care for more than a year, but less than two years. All the caregivers were related to their clients with four caring for their sisters; two caring for their brothers and brother-in-law; and one caring for her aunt (See attached appendix).

#### **4.3 Emergence of findings**

As research respondents in the current study reflected on their perceptions of the social support services in the home-based care programme, it became evident that, although each participant's experience was unique, there were common experiences about the programme, which some respondents were not happy about, and which appeared to have had a negative impact on their health.

Several themes emerged from the data such as: poverty; lack of social support; burnout; social isolation; stigma and discrimination; the negative effects of caring such as hopelessness, anxiety, and depression; fear; the need for training; patients' mood swings; and the issue of poor referral system experienced by caregivers of PLWHA. All study participants reported the same concerns except for three themes: burnout; client's mood swings; effects of caring, which were reported by caregivers only. Similar themes will be reported separately for clients and caregivers, but under one main heading.

## **4.4 Summary of findings**

### **4.4.1 Poverty**

#### ***4.4.1.1 Clients' responses***

Poverty was an overwhelming concern which made life difficult for everyone. HIV/AIDS clients reported that they were already on ARV therapy, and believed that the drugs could only work if they ate healthy food. All clients had a belief that a sick person needs healthy nutritious food to boost his or her immunity. Clients reported that - apart from food - they wanted money to buy items not included in the list of home-based care food items such as detergents.

Majority of the clients were bitter about the fact that, at one point, they had been included in the list of people to receive food parcels contained in the food baskets supplied by the Ministry of Local Government. However, once their CD4 cell count improved, they were cut from the list of beneficiaries to receive these food parcels. According to study respondents, ARV therapy was not perceived as a cure for AIDS,

and they therefore questioned their later exclusion from receiving the food parcels. A participant in a focus-group stated:

We are advised to live positively with the disease. If I live only on mealie-meal and porridge, how nutritionally are they contributing to my sickness? I need something that will boost my immune system for me to live longer. Lack of a balanced diet aggravates my condition. Currently I am on ARVs because my CD4 cell count was below 200. Because I do not have enough to eat, these tablets are not working, and I am not getting better.

The same concerns were raised by six other clients. They voiced the need for the government to include financial support in the form of a grant to all PLWHA on antiretroviral therapy. They further suggested that the food parcels be given permanently irrespective of their CD4 cell count to solve their problem of poor nutrition, which otherwise would affect their compliance. The other problem is the issue of supplies. The supplies are not readily available for example mattresses and wheelchairs. Some of us need wheelchairs to aid us in walking. We would love if adequate stock of these items is kept at our health facilities where we are supposed to get them. At the beginning of the home-based care programme, ward meetings were conducted where people were told of all these, and turn to wonder why they are not made available to us.

#### ***4.4.1.2 Caregivers' responses***

Caregivers expressed the lack of food and money as a barrier to caring, as well as a lack of other home-based care materials such as mattresses with protective covering so as to

avoid daily washing. They stated clearly that they know where to get these supplies; the problem is that they are always out of stock except for hand gloves. A caregiver explained:

Mattresses should wholly be covered in plastic, not half covered. The government supplies other home-based care materials like hand gloves: we are very happy for the supply because they are always in stock, and we always receive the quantity we request for; if they can do the same for napkins.

All caregivers were in support of the supply and use of hand gloves as they serve as a means of protection against contracting HIV virus, and they highly commended the government for that.

According to caregivers, the lack of food and money made the care-giving process difficult because they were unable to meet all the needs of the client. Caregivers further reported that they could not provide all of what clients demanded. This proved to be frustrating to both the client and the caregiver. One caregiver had this to say:

You know what, madam? If the government or any organisation was prepared to help us with all what we need, especially food and money, we wouldn't be complaining. I am not working as well as my sister whom I am caring for. She likes sweet stuff and fruits, and there is no money to buy such food items, so what must I do? I know the government is doing something to help us, but it is not enough, and again the food basket is not for each and every client on home-based care like my client. So how do I help her? I can't even join the Drought Relief Programme.

During the prolonged drought in Botswana in the 1980s, the government launched a large scale Drought-Relief Programme (DRP) to assist disadvantaged families. The programme is a form of employment, but a temporary one, and people engaged in the programme are paid a monthly wage to sustain their living. So the caregivers thought, if they had a chance of joining the programme, it would assist them through the little income they would be earning to reduce poverty in the household.

Providing care in the home was seen as challenging by both caregivers and their clients because they felt it drained them emotionally and economically. Because of the sheer burden of care-giving, caregivers were unable to engage in the Drought Relief Projects. One caregiver had this to say:

I can't even help myself with namola leuba (The Drought Relief Programme) because I am always here with the client. I can't leave her alone as her condition changes time and again, so people must help, government alone can't manage. Capable and willing individuals must come forward and support us.

#### **4.4.2 Lack of social support**

##### ***4.4.2.1 Clients' responses***

The lack of social support was the second main theme that emerged from the data analysis, and had sub-themes, which are: emotional support, spiritual support, financial support, and material support.

Social support is defined by Thoits (1995) as those functions performed for the individual by significant others, such as family members, friends and co-workers. Both clients and caregivers reported little or no support. The support received was mainly in the form of foodstuffs, blankets, and assistance in the home from few willing individuals who could afford it.

HIV/AIDS clients who reported receiving support said that the support was coming mainly from their church or prayer group, but not on a regular basis. For others, assistance came from their support group, such as those at the Shelter for the Hopeful Community, and to a lesser extent from relatives and friends.

A client explained:

We have a support group at the Shelter for the Hopeful Community. We assist one another all the time. If one of us is not well, we visit the family and assist in whatever way: like cleaning the yard, counselling the family members, and end up by giving a prayer.

The other client said:

I feel we should all belong to a support group of PLWHA, because from my observation those being assisted at the Shelter for the Hopeful Community are better off than the rest of us in terms of helping one another, and accepting themselves in living positively with the disease because they work as a team, and are supportive of one another.

Most clients depended on family members and home-based care volunteers, who were reported not to be coming as regularly as expected.

#### **4.4.2.2 Caregivers' responses**

As for caregivers, they had few relatives constituting a support system. Caregivers described the kind of support received from the few relatives as emotional, medical, informational, and physical support, though at a very small percentage. According to the respondents, they felt that there was no social support for those infected and affected by the epidemic. Caregivers linked the lack of social support to the stigma attached to HIV/AIDS.

#### **4.4.3 Emotional support**

##### **4.4.3.1 Clients' responses**

Emotional support was viewed by participants as important because it dealt with their feelings. They felt that there was little respect for PLWHA from the community and that emotional support was important in helping them deal with the disease process.

One client explained:

This disease has no cure, and we are always anxious, and therefore we need emotional support. It would help us cope with the disease.

##### **4.4.3.2 Caregivers' responses**

Caregivers said that if people were to encourage them through the provision of support, they would not be experiencing such problems as burnout, stress, and feelings of depression.

#### **4.4.4 Spiritual support**

##### ***4.4.4.1 Clients' responses***

HIV/AIDS clients felt that spiritual support was a vital component of care, especially for people with terminal illnesses like AIDS, who, and are on home-based care. They believed that members of the community, especially spiritual leaders, could play a vital role in this aspect of care for ill HIV/AIDS clients and their caregivers. Clients said that as PLWHA, they needed to feel supported in their search for spirituality, regardless of their approach or their faith. One client said:

Since there is no cure for AIDS, the only solution is to bring ourselves closer to the Lord, so that we die a peaceful death. Spiritual counselling is not forthcoming as we had wished, but it is very much effective and comforting, and it also gives some of us the strength and hope that a cure for this deadly disease will be found, and we will stop dying, and I am appealing to those with the skill to help us because we need those prayers.

##### ***4.4.4.2 Caregivers' responses***

Caregivers were equally concerned about the lack of spiritual support. They also spoke of it as instilling a sense of hope that the patient would recover. One caregiver said that during her school days they were always taught that, during difficult times, people must pray, and said that the present situation of HIV/AIDS warranted people to pray a lot for those who are infected and affected and to ask that a cure for the deadly disease be discovered.

#### 4.4.5 Burnout

Burnout was not a concern for HIV/AIDS clients on home-based care; but was overwhelming for caregivers. The concept of burnout was developed by Maslach and Jackson (1986) and they defined the concept as a psychological state of emotional exhaustion, depersonalisation and reduced personal accomplishment that may occur in individuals who work in people related occupations. The majority of caregivers expressed a feeling of being very tired as a result of caring. One participant said:

I am tired, but there is nothing I can do. As long as she is still here, I have to do my level best to assist, even if I am tired. She is my sister, and I love her and so I will continue with the caring despite the difficulties I am going through.

Another caregiver said:

We can't run away from what we are doing, but if we had support, our problems would not be considered as major problems like is the situation now. The other problem that I see worsening our situation is that we have a lot to do in terms of providing care not only to the terminally-ill, but to all family members, all on your own without anyone helping you. So let all pray for a cure for this disease. Without a cure, I foresee a situation where our problems would never end.

#### **4.4.6 Social isolation**

##### ***4.4.6.1 Clients' responses***

HIV/AIDS clients on home-based care voiced the issue of social isolation. Very few clients had no problems with social isolation. They reported good social interactions with the people they were used to, even before falling sick, such as friends. Friends either came to check on how they were doing, or would call them. The majority, however, reported experiencing social isolation, which they believed was as a result of the stigma that people attached to the disease. They reported rejection by even close friends and some community members, and said this impacted negatively on their health, because they reported that if you are all by yourself, your mind is never free. You have many questions in your mind without answers, blaming yourself and other people for your illness. They perceived the limited social interaction as changing them from competent, healthy social beings to that of inadequate and dysfunctional (Mayers 2000), and this made them stressed, something they described as not good for their poor health. One client lamented:

People have decided to isolate me just because I have AIDS, but I am not crippled. There are times when I feel weak, and times when I feel strong that I can help in the community, but just because I have AIDS people don't treat me well like the rest of the community members, and this is frustrating.

##### ***4.4.6.2 Caregivers' responses***

Social isolation was also prominent among caregivers of PLWHA.

One caregiver said:

Most of the time we are home with the client because of having no one to help us. As a result, we end up not participating in community activities. Because people do not know what we are going through, they turn their backs on us, as we fail to honour their wedding invitations. Yes, a few others have decided to avoid us because we are nursing people with HIV/AIDS.

Another caregiver said:

My sister, I want to agree with the above speaker, because of a lack of knowledge and understanding by community members of what we go through, the mere fact that we don't show up at the social gatherings is a big problem. As a result they isolate us. Some do that because of the AIDS stigma, and others, I believe is through lack of knowledge. My request is that people be taught once again about AIDS, home-care, and support. To care for a patient who can't do anything for herself is frustrating. At times you go out for just a few minutes, she becomes angry with you, and they get angry out of nothing, and people do not understand all these issues.

#### **4.4.7 Stigma and discrimination**

##### ***4.4.7.1 Clients' responses***

People on home-based care living with HIV/AIDS expressed their disappointment with how people stigmatized and discriminated against them. PLWHA have an impression that people discriminate against them because they have a condition that is transmitted

sexually, and therefore do not deserve support. This has a moral dimension, where the disease is associated with sexual promiscuity and bad behaviour. PLWHA feel that such stigma and discrimination affect their access to health care, social interaction, adherence to treatment and social support. A client reported:

Since being diagnosed with this deadly disease, I have accepted myself so that I live positively with the disease. The situation is made worse by people who don't want to assist us, stigmatise us, discriminate us, but to me AIDS is just a disease like any other disease, so people must stop discriminating against us. Who knows? Tomorrow it could be one of them.

Another client said:

It is not AIDS which kills us, but the negative attitudes from people. We still deserve proper treatment; we have the right to life like other people suffering from tuberculosis, hypertension and other illnesses.

In a focus-group discussion the overwhelming majority of study respondents were not happy about the stigma and discrimination that they received from the rest of the community members.

A client lamented:

Look, we are now over twenty years since the first case was diagnosed in 1985 in this country. How long is it going to take people to accept HIV/AIDS as a disease like tuberculosis, cancer, and hypertension, just to

mention a few? They must change and reach out for us instead of stigmatising us. The more the community discriminate against us, the more we get disturbed emotionally and physically.

#### **4.4.7.2 Caregivers' responses**

Similar to PLWHA, caregivers reported experiencing stigma and discrimination. Caregivers said that there are instances where other family members and the rest of the community look at them as if they are the ones responsible for their children's infection. As a result, people looked down upon them and stigmatised and isolated them.

#### **4.4.8 Effects of caring**

##### **4.4.8.1 Caregivers' responses**

More than three quarters of the caregivers described care-giving as very demanding and daunting, leaving them stressed, depressed and without hope, impacting negatively on their health. They further reported that the caring process confined them to their homes to an extent that they do not have time to themselves and to be with their families. Though they expressed the demanding nature of the home-based care, caregivers believed that if they had the necessary love and support from the health care providers and the community at large, they would not consider it much of a problem because the love and support would reduce the burden of care. The mere fact that AIDS has no cure kills the whole spirit of caring, and one becomes helpless and hopeless, therefore assistance of any form is welcomed.

Caregivers reported having broken hearts from witnessing their HIV/AIDS clients suffering only for them to die after that long struggle. One caregiver said:

Since I started taking over the care-giving process, following the death of my mother, I always have minor headaches to an extent that I went to the clinic where I was told that I have signs and symptoms of high blood pressure. I agreed with them because I could feel the stress in my body. I don't know what wrong we have done. How come other diseases like tuberculosis have drugs to cure them, and this AIDS doesn't have? The big problem is lack of support. If we had all the support needed, the programme of home-based care would be a good programme.

Other caregivers had the same sentiments, and stressed the importance of strengthening the referral system in addition to improving social support. The referral system was seen as important for the effective implementation of a home-based care programme. They saw this aspect of caring as increasing their poverty because they had to hire a taxi to and from the hospital for their client's check-ups. They reported that this aspect on its own added more pressure and stress on them. They further reported that most of the time, especially on discharge from hospital, there was nothing to guide them on how to look after the patient, nor information on his or her treatment. Caregivers pointed at all these anomalies needing urgent attention to improve the programme of home-based care. Without effective discharge planning, the home-based care team may not be aware of the needs of the sick people and their families undergoing home-based care. Such planning is expected to start at the hospital while the patient is still admitted for continuity of care.

Caregivers were also not happy about the clinic staff and community home-based care team at the Siga home-based care centre. They reported that both the clinic staff and home-based care team were only active at the beginning when they register clients, only to disappear in the process of care-giving. They further noted that the programme would work very successfully if the clinic and home-based care staff made an extra effort to enhance collaboration through information and skills sharing.

#### **4.4.9 Fear**

##### ***4.4.9.1 Clients' responses***

All the nine HIV/AIDS clients reported the experience of fear at different stages of their life. Their first stage of fear was at the time of taking blood samples for testing and the time when the results of the HIV test were revealed, and if declared positive, the HIV-positive client went through a second stage, where concerns were felt about the absence of a cure for AIDS, and for the prospect of stigma and discrimination. Depression and despair thus followed the initial HIV-positive diagnosis.

The majority of the clients contributed their failure to live positively with the disease to fear, as one of them said:

I actually developed a drinking problem after learning that I was HIV-positive. I thought that drinking would help me die faster because I didn't want to stress anyone in my family, in terms of having to provide care for an unknown period of time. There were no ARVs by then.

According to the clients, fear was as a result of thinking about what other people were saying about PLWHA, the type of death they would experience, and this, according to them aggravated their condition. The condition was then made worse by a lack of support in the form of on-going counselling.

#### ***4.4.9.2 Caregivers' responses***

Their fear was reported mainly as the fear of contracting the disease, and the accompanying stigma and social isolation.

#### **4.4.10 Need for training and support**

##### ***4.4.10.1 Clients' responses***

All clients expressed the need for training and support. Clients believed that education about the disease was most vital to them, that is: how they ought to handle themselves. They wanted to be invited to attend educational talks and workshops to learn from one another.

They reported that they would love to meet with other HIV/AIDS-positive clients and form a support group of PLWHA for purposes of sharing ideas. In a focus group discussion one client responded:

My friend told me that in their area they have a support group of PLWHA. It would be good if we have something similar to that in our area, because this on its own is a motivator to learn that you are not the only one suffering from AIDS, and through this interaction we would be in a position to learn about the different coping skills from others, and be able to live positively with the disease.

#### *4.4.10.2 Caregivers' responses*

Caregivers expressed the need for training and support. They believed that, if they were well equipped with the necessary skills and knowledge, they stood a better chance of providing a high standard of care to their HIV/AIDS clients. They reported that, because of the ethical ordinance of confidentiality surrounding HIV/AIDS diagnosis, training and support becomes a necessity in order to prevent cross-infection as a result of ignorance. They further noted that, since they had not been officially trained to provide care, they felt that they were not functioning as part of the health care team in making the home-based care programme a success. They requested that they be called for workshops (Caregivers workshops) to be able to share ideas and learn coping skills from one another.

We are the caregivers of these people, but the sad part is that we do not know what they are suffering from. So, if we could be trained on what to do, how to do it, and what to expect, it would reduce our uncertainties as caregivers, and make the care-giving environment acceptable, and interesting. You will find that some of us, on joining the programme, do not know where to get the supplies for our clients because no education or needs assessment is done before joining the programme. So, if at least during the course of the care, we are provided with some form of education, it would make work easy for us, and would reduce lots and lots of stress we go through because of the caring process.

#### **4.4.11 Referral system**

##### ***4.4.11.1 Clients' responses***

All HIV/AIDS clients expressed dissatisfaction with the referral system in place. They often complained that as a result of the poor referral system, they stayed at home for a long time after being discharged without anyone from the home-based care team having visited them. They expressed the concern that at times they felt that they had been discharged not because they had improved, but because they were considered not important because of the type of the illness they were suffering from, despite their need for care. They therefore expressed a need for improvement in the referral system so that they could be immediately followed-up at home and assisted there, if need be.

##### ***4.4.11.2 Caregivers' responses***

Caregivers were equally unhappy about the referral system. They said that they were expected to report to the nearest clinic if they needed help, but in the majority of cases, they were not assisted, especially with regard to transport. This, they maintained, was a problem, especially to the majority because they were not working, and did not have money to hire taxis to transport their clients to and from the hospital or clinic. Their other concern was lack of communication among the health facilities (the clinic and the hospital), and they called for urgent improvement in this area.

#### **4.4.12 Mood swings**

##### ***4.4.12.1 Caregivers' responses***

Half of the caregivers reported experiencing problems with mood swings among their clients. One caregiver said:

She wants me home all the time. Now because I don't want to hurt her, I try by all means to hang on all the time. You go out, she becomes angry, and you will feel bad about it.

Another caregiver explained:

The problem is the nature of the disease itself: that it is transmitted sexually, it's harsh, and has no cure. All these make HIV/AIDS clients to have mood swings because they feel we do not care if we leave them and rush somewhere because they have AIDS, but it is not like that. We are trying our best to make them happy by offering the little we can.

#### **4.4.13 Summary of Findings**

Participants' perceptions of their experiences with the social support networks varied along a continuum from satisfaction to dissatisfaction. All participants felt that the home-based care programme was good, considering that health facilities are always congested, and also that there was a shortage of professional staff to provide care at the health facilities. Nevertheless, participants were concerned about the implementation of programme itself. They said that lack of proper implementation and support made them vulnerable to stressful situations that were not good for their health. At the same time, they appreciated the efforts made by the government in providing free ARV therapy, and other home-based care supplies such as hand gloves for the protection of caregivers against contracting the HIV virus.

## CHAPTER FIVE

### DISCUSSION

Chapter five discusses the results presented in chapter four comparing them with findings from other studies in relation to how HIV/AIDS clients and their caregivers perceive social support services, while receiving home-based care. To gain maximum benefit from home-based care-giving, HIV/AIDS clients and their caregivers need maximum social support. While many studies have been conducted in the past on HIV/AIDS and home-based care both in Botswana and elsewhere (Fako and Gary Linn; 2006; Kabuluzi 2005; Katapa 2004; Mathebula 2000; Mbata-Ndaba 1998; Mbata-Ndaba and Seloilwe; 2000; Orner 2005; Shaibu 2006), the researcher in the current study did not come across any study which was looking specifically at the views of PLWHA and their caregivers concerning social support systems in the home-based care programme. Little therefore is known about how PLWHA and their caregivers perceive social support services available to them while receiving home-based care services. The literature has shown, however, that many HIV/AIDS-affected families experience very limited support, often because of the stigma associated with the disease (Brown and Powel-Cope 1991; Kelly et al, 1996; P-Cope 1994; Stajduhar 1997). This study therefore provides for the first time perceptions of HIV/AIDS clients and their caregivers of a community home-based care support programme in Botswana.

According to the study findings, the majority of personal care provided to terminally-ill patients continued to be provided by family members especially women. Studies conducted in the past presented similar findings (Emanuel et al, 1999; Lindsey et al, 2000; Mbata-Ndaba 1998; Ministry of Health, 1998). The fact that personal care is more often provided by women tends to increase their risk of HIV-infection because of

the caring practice of not using hand gloves. In addition to being infected with the HIV virus, they tend to be poor, for some caregivers often leave their employment to provide care to their sick relatives (Lindsey et al, 2000; Fako and Gary Linn 2006). In this study, most caregivers never had official employment, and the poverty thus experienced was not as a result of having left employment.

Poverty emerged as a major issue in this study. Most HIV/AIDS clients, because of their ill health, had given up their employment. Poverty issues raised in the study reflect the findings of other published studies (Fako and Gary Linn 2006). The overwhelming poverty thus experienced by respondents in the current study was as a direct result of the loss of employment, because at an earlier stage, many clients had been the sole breadwinners for their families. Similarly, poverty-related factors affect households and community coping strategies. Previous studies conducted elsewhere in sub-Saharan Africa have showed that poverty is a common phenomenon among PLWHA and their caregivers, as well as a prevailing lack of basic resources, which impinges once again on employment, and social life (Katapa 2004; Orner 2005; Shaibu 2006). With an overall lack of food and money, the conditions of HIV/AIDS clients become further aggravated, thereby reducing the effectiveness of ARV therapy. The health advice of taking ARV treatment after a meal, for example, becomes inappropriate and further tends to client's failure in complying with the treatment itself.

Economic resources play an important role in a family's perception of well-being. Insufficient income reduces access to resources by households that might make coping with the illness and care-giving more bearable. What needs also to be kept in mind is the aggregative effects of the HIV epidemic, for it will not only impoverish individuals

and communities, but will also erode the capacity of the socio-economic system through losses of human resources (UN Special Session on HIV/AIDS, 2001). We have seen in the current study that loss of human resource from HIV/AIDS was common (Fako and Gary Linn 2006). There is thus an enormous strain placed on the capacity of families to cope with both the psycho-social and the economic consequences of the illness, such that most families experience great distress and often disintegrate as social and economic units (UN Special Session on HIV/AIDS, 2001). With traditional systems of support declining, support mechanisms should be in place to help those in need to be able to cope with whatever problems they are faced with, either of living with HIV/AIDS or caring for an HIV-positive client.

Continuous adherence to ARV therapy is a powerful predictor of survival for individuals living with HIV/AIDS (Mills et al, 2006). Barriers to ARV adherence include financial constraints, a factor HIV/AIDS clients and their caregivers in the current study mentioned frequently (Weiser et al, 2003). Given financial constraints, the typical family is unable to live a normal life with all the resources they need, and these impacts negatively in turn on the health of PLWHA and their caregivers. It is important therefore that issues of poverty are dealt with decisively in order to reduce the burden faced by HIV/AIDS clients and their family members, as well as improving the quality of life itself of PLWHA and their caregivers.

The issues of burnout and stress cannot be overemphasised given the results of the current study. All the caregivers reported experiencing burnout. Individuals in the helping profession and those providing care to terminally-ill patients are subject to unique stressors that may lead to burnout. Overwhelming fatigue denies caregivers the

potential to provide quality care to their sick family members, as well as putting them at risk of developing some illnesses. These observations are consistent with results from other studies (Bellani et al, 1996; Silverman 1993). According to their results, burnout in the HIV/AIDS field manifests itself more sharply and more strongly than in other fields. This results from multiple factors. These factors include inadequate knowledge and support, social stigma, fear of being infected, and all these reduce efforts towards effective health care.

HIV/AIDS care-giving is a difficult and challenging role which needs a great deal of psychological and emotional support in the form of counselling. Counselling was identified by both clients and their caregivers as an important element in the caring process. There is a need therefore by all those responsible to continuously provide counselling to both PLWHA and their caregivers. With continuous counselling, individuals tend to understand their problems better and are able to adapt more effective coping strategies.

PLWHA and their caregivers in the current study talked at length about spirituality and the need for spiritual support, especially when dealing with death and dying due to HIV/AIDS. For most respondents, spiritual support was seen as an important component of care in the context of CHBC, and can offer both PLWHA and their caregivers' inner strength and hope. It follows, therefore, that continued spiritual support is required for both HIV/AIDS clients receiving home-based care services and their caregivers. Religious conversations represent a coping method and can play an important role in the meaning-making process (Park and Folkman 1997, quoted in Plattner and Meiring 2006). HIV/AIDS clients and their caregivers showed a desire to

communicate with God through frequent prayers since these prayers instilled high levels of hope and feelings of being loved. The present results support previous findings (Siegel and Schrimshaw 2002) that people living with HIV/AIDS believe that they receive substantive benefits from their religious and spiritual beliefs. Some of the benefits include feelings of strength and empowerment, and relief from the fear and uncertainty of death. Daily spiritual experiences might mitigate physical, cognitive, and emotional forms of burnout experienced by both HIV/AIDS and their caregivers, and need to be provided.

Experiences of stigma and discrimination were common among study participants, and were major obstacles in the provision of social support. In Botswana, it has been found that it is the presence of stigma which fuels the HIV/AIDS epidemic, making it more difficult to access care and to engage communities in prevention activities (AIDS/STD Unit, 2002). The existence of stigma towards PLWHA and caregivers of PLWHA is well documented and has to be taken into consideration, since it affects access to health care, medications, adherence, social interaction and support (Carr and Gramling 2004; Chesney and Smith 1999; Goldin 1994; Lindsey et al, 2003; Maneesriwongul et al, 2004). As social interaction becomes more limited, participants' perceptions of themselves change from appearing as competent, healthy social beings to that of inadequate and dysfunctional individuals (Mayers 2000). Living with HIV/AIDS impacts on the person's relationship with others, and this erodes the perception of social support to a very low level, impacting negatively on those living with HIV/AIDS, and on those caring for PLWHA.

These findings are consistent with other studies on stigma, where the findings revealed that the experience of social rejection caused by stigma affects access to health care, social interaction, adherence, and social support (Carr and Gramling 2004; Lindsey et al, 2003; Maneesriwongul et al, 2004; Simeza 2002). There is thus an urgent need for interventions that would help reduce the impact of stigma, discrimination and social isolation on PLWHA and caregivers so that they can achieve a higher level of wellness, increase their life span, continue in the workforce, and improve their quality of life (Carr and Gramling 2004). HIV/AIDS stigma must be acknowledged and reduced to advance HIV prevention and HIV/AIDS care in a variety of settings (Rutledge and Abdell 2005). HIV/AIDS clients in the current study stated that they deserve to be treated like any other person suffering from any terminal illness, because they have the right to life, right to health, and the right to treatment. In line with this finding, Elliot and Gold (2005) reported that respecting, protecting, and fulfilling the human rights of people living with, and vulnerable to, HIV/AIDS is an essential element of an ethical and effective response to the AIDS epidemic.

Community ignorance of the practice and effects of stigmatizing and discriminating against PLWHA and their caregivers has impacted negatively on the HIV/AIDS campaign. This stigmatisation and discrimination has consistently resulted in people not accessing the services provided in the HIV/AIDS programme. These negative attitudes stem from ignorance and a limited understanding of the disease, and points directly to the urgency with which public awareness about HIV/AIDS should be created. Building up such awareness would have two advantages. Firstly, the community would be sensitised to the experiences of caregivers and, instead of discriminating against them, they would be inclined to reach out to them. Inappropriate

forms of support might also be thus eliminated. Secondly, caregivers, being reassured of an understanding response, would come forward and actively seek support.

With regard to fear, HIV-positive clients, when they first heard of their diagnosis, were understandably frightened by the prospect of sickness and death. There is thus some denial, which becomes a barrier to disclosing one's HIV-positive status to family members. This denial is further rooted in the fear of stigmatisation and discrimination. Those who are found positive tend to have a lot of questions: where and how they got the virus, why them, and community's feelings about them - a typical form of self interrogation at this stage. The mere fact that there is no cure for the disease exacerbates such fears to the degree that the HIV-positive client knows that at some point in time, he or she is going to die. Not only do they fear death, they also fear the harsh reality of HIV/AIDS, and prolonged wasting. Fear was also revealed by earlier studies conducted in the USA (O'Donnell et al, 1987), New Zealand (Van Wessen & Woodman 1994), and Northern Ireland (Steele and Melby 1996).

To the caregivers of PLWHA, fear and apprehension were also experienced. Their fear was mainly that of contracting the virus, and of stigma, rejection and discrimination. With this fear, the capacity to make appropriate decisions to help the client becomes compromised. Thus the need for support to be given to caregivers is justified in order to help them overcome all these problems. The experience by caregivers of PLWHA in the current study was not unusual since previous studies had already showed that fear among HIV/AIDS clients and their caregiver is common (Akisanya and Rouse 1992; Breault and Polifroni 1992; Maneesriwongul et al, 2004; Simeza 2002). To reduce

issues of fear in both PLWHA and caregivers of PLWHA, there is need for continuous counselling, education and support.

Information about HIV/AIDS and home-care is not static. People need constant upgrades in knowledge in order to be in a position to deal effectively with the disease. Knowledge is important because it helps the individual in making informed decisions. Participants in the current study perceived that the poor quality of information made available to them was a barrier in the provision of quality care. Training and education is thus an important component of a CHBC programme, assisting PLWHA on how best to deal with the disease. Equipped with adequate information, terminally-ill HIV/AIDS clients may have better opportunities to make end-of-life care decisions that are in accordance with their wishes.

As for caregivers, since they are not health professionals, they need training to be in a position to know what to do, how to do it, and when and how to take precautionary measures in order to avoid being infected. With the introduction of antiretroviral therapy, information about the physical changes, medication use and death is necessary to caregivers of PLWHA. They felt that having all the necessary information would help them make informed choices, and be in a position to provide care without fear. The perceived lack of proper guidance was seen as contributing to a failure in achieving their objectives of providing quality care to PLWHA, and at the same time was seen as placing their lives at risk. Training, education, and support tend to create a favourable environment, where caregivers would develop a keen interest in their work, even if it is stressful and depressing. The feeling was expressed that, if one had simply joined the home-based care programme without HIV/AIDS specific knowledge and caring

experience, as was the case with some of the caregivers in the current study, then it was necessary to obtain continuous guidance and support.

The need for establishing HIV/AIDS support groups, therefore, was seen as imperative because such support groups would serve as a learning forum, thus closing the existing knowledge gaps. At the same time, as HIV/AIDS clients and their caregivers interact within the groups, they might learn coping skills from well-experienced members who had been in the programme for sometime. These findings are consistent with the results from previous studies which showed that health professionals such as nurses and family caregivers often lacked the information and skills essential for providing appropriate care (Mbata-Ndaba and Seloilwe 2000; Maneesriwongul et al, 2004; Simeza 2002). Without adequate information, people are unable to manifest more coping skills, and end up being stressed and frustrated compared to well-informed participants, and this impact negatively on their own health and on the care provided. A study by LaMontague (1987) compared to this finding revealed the same findings that families who receive detailed information about the condition of the patient manifest more vigilant coping skills than those without such information. Those with knowledge and skills experience less stress from the caring process as this acts as a cushion for them.

Caregivers of PLWHA also need support groups. Support groups with their focus on awareness, shared experiences, supportive and helping relationships are useful in helping caregivers of PLWHA to manage stress and to enhance their capacity and effectiveness to work with their clients (Grossman and Silverstein 1993). Support groups also help participants feel less isolated and provide a welcoming space to share feelings with regard to such difficult issues as the prospect of death, and the

accompanying feelings of anger, helplessness, and loss (Grossman and Silverstein 1993). With the prevalence of HIV/AIDS still high in most African countries, people should be equipped with adequate knowledge and skills of caring for PLWHA at home. With the introduction of ARV therapy, more HIV/AIDS clients are going to live longer, and will need to be cared for at home, and therefore the urgent need exists for building and strengthening mechanisms that will promote and support learning from each other and the sharing of information and experiences with regard to home-based care at all levels.

The referral system is an important component of a home-based care programme. Without proper feedback and communication between the three levels of health care, namely the hospital, the clinic, and the home as is the case of Botswana, HIV/AIDS clients and their caregivers are still likely to suffer because of the delays resulting from lack of current information about the clients, especially those newly registered. Poor referral system impacts negatively on PLWHA and their caregivers in that (i) People are not assisted instantly, and this may aggravate their conditions especially HIV/AIDS patients, (ii) It is costly in the sense that they spend their time and the little finance they have to seek more care elsewhere (iii) loss of trust and confidence on the part of government health care facilities, (iv) Increases morbidity and mortality in PLWHA. Strategies thus need to be put in place to try and improve the referral system.

To live with HIV/AIDS is extremely challenging both physically, mentally and emotionally, causing enormous stress, anxiety and depression (Mbata-Ndaba and Seloilwe 2000; Lindsey et al, 2003; Stetz and Brown 2004). There is thus a great need for education, counselling, and support for PLWHA and their caregivers in order to

equip and empower them with the appropriate skills for dealing with the physical and emotional strains. HIV/AIDS clients and caregivers both require access to a regular forum where they can experience understanding and empathy. As for caregivers, such a kind of forum would help them gain a respite and help them to share the psychological burden of helping PLWHA. Despite all the hardships, caregivers in this current study demonstrated a sense of interest in their clients; and many caregivers stated that being able to give even a little bit, in whatever form, restored some sense of dignity to them.

Caregivers of PLWHA in this current study experienced varying moods from their HIV/AIDS clients but associated such behaviours with the harsh reality of the disease, its prolonged wasting, and its unpredictable outcomes. They saw this as something beyond their control, and that they would keep on providing care and support irrespective of what was happening between them and their clients. With a coordinated response, the burden of care would be minimal with less fear, stress, anxiety, and depression unlike the current situation, where people provide care under stressful conditions.

This study has added an important aspect of how PLWHA and their caregivers view social support systems in the home-based care programme. The study has shown that HIV/AIDS clients receiving home-based care and their caregivers are not entirely comfortable with the support they receive from both health-care professionals and the community at large. The study is therefore aimed at closing the existing gap in support for family care-giving of PLWHA and their caregivers. The current study has demonstrated why PLWHA and their caregivers need to be supported. Problems which

emanated from this study have also been identified in previous studies, and need to be addressed for better implementation of the home-based care programme

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## **CHAPTER SIX**

### **CONCLUSION, LIMITATIONS AND RECOMMENDATIONS**

The study of HIV/AIDS clients and their caregivers' perceptions of a community home-based care support programme has remained a largely unexplored area. To this end, the present study has attempted to extend the current understanding of the context of HIV/AIDS as follows:

Firstly, without adequate social support, the home-based care programme may be seen to fail in its objectives of providing quality care to terminally-ill HIV/AIDS clients in a more conducive home environment, even if free antiretroviral treatment is available.

Secondly, an overwhelming majority of participants reported encountering problems of stigma, discrimination, social isolation and fear. Stigma and discrimination have a considerable influence on people living with and affected by HIV, as well as on their health-care providers, particularly in Botswana, where the burden of AIDS is so significant. As a result, stigma has emerged as one of the major themes and a limiting factor in primary and secondary HIV/AIDS prevention owing to the fear of being labelled "HIV" infected, and or affected, and needs to be addressed through the community being made aware of stigma and its negative consequences.

Thirdly, poverty was seen by both HIV/AIDS clients and their caregivers as a major problem. All study participants were of the opinion that all HIV-positive clients on ARV therapy ought to be given a basic grant or at least a food basket irrespective of the status of their condition in terms of their CD4 cell count. High quality food distributed

among PLWHA can prolong productive life and increase the time leading up to an AIDS defining illness and ultimate death.

Fourthly, the importance of a social network was seen as essential in creating an environment which protects the individual's health, and that the encouragement of these networks would facilitate coping and resilience. In HIV/AIDS care, a continuum of care is important, for it involves a network of resources and services that provide holistic and comprehensive support for ill people and their families.

Fifthly, the findings of the current study suggest the importance for members of the home-based care support system to be educated about, and sensitised with regard to issues concerning HIV/AIDS. Such endeavours could incorporate a two-pronged strategy. They could provide knowledge about how the disease is transmitted, thereby dispelling myths and misconceptions; and also descriptions of its impact, thereby bringing home the predicament of the caregiver. With this information, caregivers would be less likely to experience symptoms of depression, anxiety and stress, and would be further willing to provide care until the death of their HIV/AIDS clients.

The current study also points to the urgency with which public awareness about HIV/AIDS should be created. Building up awareness would have two advantages. An initial advantage would be that the community would be sensitised to the experience of caregivers, and, instead of discriminating against them, they would reach out to them, while inappropriate support would also be eliminated. Secondly, caregivers, having been reassured of an understanding response, would come forward and actively seek support.

In addition to the stated problems, the current study also revealed issues of burnout as a result of fatigue from lack of rest, stress and anxiety, mental-health caring effects, and a lack of training and education. Despite all the difficulties, however, caregivers were still prepared to care for their sick individuals, but would much appreciate being assisted in one way or another in order for them to provide quality care to their clients. Support is the strongest independent determinant for recovery, though more aggressive alternative strategies to support PLWHA and caregivers should be promoted. An effective CHBC programme can yield major health and social benefits, starting with the clients and their families.

Both HIV/AIDS clients and their caregivers highly appreciated the efforts by the government of Botswana in providing free antiretroviral therapy to PLWHA, but felt nevertheless that a lot still needed to be done to improve the home-based care programme in general. Respondents felt that, since resources are limited at the hospitals, and that their problems are long term, the home-based care programme should be viable and well implemented to benefit the terminally-ill as intended by the government of Botswana.

### **Limitations of the study**

Data was based on self-generated responses, and the fact that HIV/AIDS is a sensitive topic might have influenced the findings of the study. Secondly, the period of data collection was short, hence the reason for a small sample size. Thirdly participants were recruited from a specific home-care support programme and may have different

characteristics from those in other programmes which do not have home- based care support.

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## Recommendations

The following are recommendations arising from the study:

- There is need for further strengthening of the referral system in place for a better integrated continuum of care.
- Non-governmental organisations, community-based organisations, and faith-based organisations need to offer terminally-ill HIV/AIDS clients and their caregivers' significant support. This will minimize all the stress and anxiety they encounter in the process of their sickness, and care-giving activities.
- The government of Botswana needs to come up with strategies that would seriously address issues of family poverty and stigma. Additional supply of food is important for the nutritional status of HIV/AIDS clients receiving home-based care, as it will boost their immune systems.
- Community home-based care volunteers need to offer work over a full day and on a daily basis to assist caregivers who are usually all by themselves and without anyone assisting them. This would give caregivers a chance to rest, resulting in less anxiety, depression and burnout.
- Continuous training and education needs to be made available, especially to caregivers of PLWHA. This would assist them to better understand how to handle their clients and how to avoid being infected.
- Innovative strategies are also required to establish effective partnerships between non-governmental organisations, and any other organisations such as community-based and faith-based organisations.

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## APPENDICES

- Appendix 1: Demographic Characteristics.
- Appendix 2: Interview Guide – HIV/AIDS Clients.
- Appendix 3: Interview Guide – Caregivers.

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## DEMOGRAPHIC CHARACTERISTICS

**HIV/AIDS CLIENTS: N=9**

<b><u>AGE- RANGE( Years)</u></b>	<b><u>FEMALES</u></b>	<b><u>MALES</u></b>
20-29	3 (33%)	---
30-39	4 (44 %)	---
40-49	---	1 (11 %)
50-59	1 (11%)	---
60+	---	---
<b><u>Sex</u></b>	<b><u>Females</u></b>	<b><u>Males</u></b>
	8 (89%)	1 (11%)
<b><u>Education</u></b>	<b><u>Females</u></b>	<b><u>Males</u></b>
Primary	1 (11%)	---
Secondary	5 (56%)	1 (11%)
Tertiary	2 (22%)	---
<b><u>Employment</u></b>	<b><u>Females</u></b>	<b><u>Males</u></b>
Employed	3 (33%)	---
Unemployed	5 (56%)	1 (11%)
<b><u>Religion</u></b>	<b><u>Females</u></b>	<b><u>Males</u></b>
Catholic	---	1 (11%)
UCCSA	1 (11%)	---
Apostolic	2 (22%)	---
Muslim	1 (11%)	---
Lutheran	1 (11%)	---
Assemblies	1 (11%)	---
None	2 (22%)	---

**CAREGIVERS: N=7**

<b>Age-Range( Years)</b>	<b>Females</b>	<b>Males</b>
20-29	---	---
30-39	---	---
40-49	3 (43%)	---
50-59	3 (43%)	---
60+	1 (14%)	---
<b>SEX</b>	<b>Females</b>	<b>Males</b>
	7 (100%)	---
<b>Education</b>	<b>Females</b>	<b>Males</b>
Primary	4 (57%)	---
Secondary	1 (14%)	---
Tertiary	2 (29%)	---
<b>Religion</b>	<b>Females</b>	<b>Males</b>
Catholic	4 (57.1%)	---
Apostolic	1 (14.3%)	---
Lutheran	1 (14.3%)	---
None	1 (14.3%)	---
<b>Employment</b>	<b>Females</b>	<b>Males</b>
Employed	1 (14%)	---
Unemployed	6 (86%)	---
<b>Relationship</b>	<b>Females</b>	<b>Males</b>
Brother	2 (29%)	---
Sister	4 (57%)	---
Cousin	1 (14%)	---

# Interview Guide - HIV/AIDS Clients

## Section I

1. Date of interview:

(Day/month/year):

--	--	--

2. Interview number:

--

3. Interview code:

--

4. Place of interview: Home

Health Facility

Others


5. Age in years:

--

6. Gender:

F	1		
M	2		

7. Please indicate your level of education:

None	0	
Primary	1	
Secondary	2	
Tertiary	3	
Non-Formal	4	

8. Current employment status:

Unemployed	0	
Employed	1	
Self-employed	2	

9. If employed, what is your income per month? (Botswana Currency).

P300-P400	0	
P400-P600	1	
P600-P800	2	
P800-P1000	3	
P1000+	4	

10. Please indicate your religious affiliation:

None	0	
Catholic	1	
Lutheran	2	
Assemblies	3	
Others(	4	

Specify

**Section II**

1. How are you coping with the disease?

.....  
.....  
.....  
.....

2. What kind of assistance do you get from the health workers?

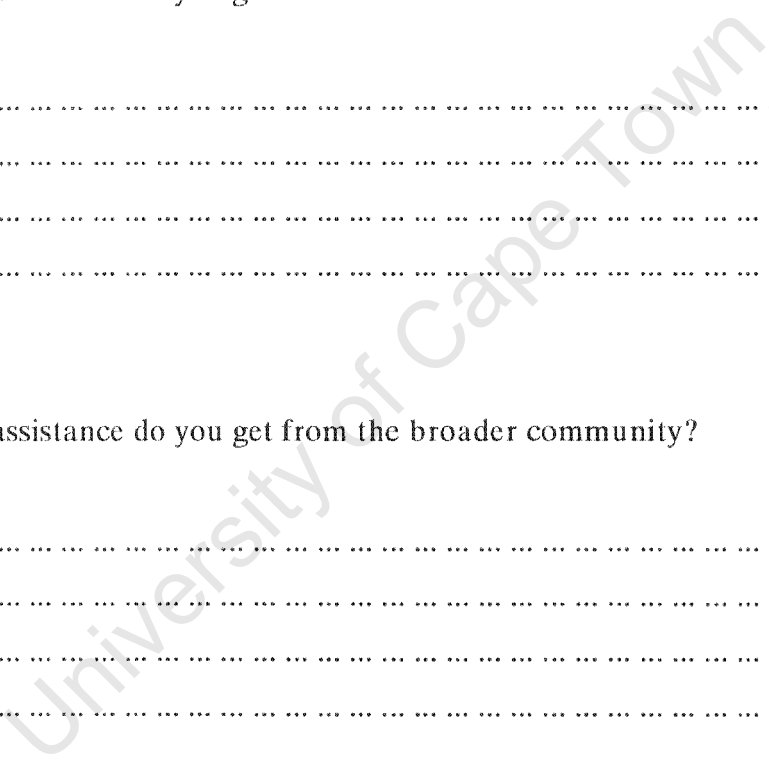
.....  
.....  
.....  
.....

3. What kind of assistance do you get from the broader community?

.....  
.....  
.....  
.....

4. What is the most difficult thing about living with the disease?

.....  
.....  
.....  
.....



5. What does social support mean to you?

.....

.....

.....

.....

6. Please tell me about the social support services available to you:

.....

.....

.....

.....

7. Who provides support?

.....

.....

.....

.....

8. How do you feel about the support you are receiving?

.....

.....

.....

.....

University of Cape Town

9. How do you think it can be strengthened or improved?

.....  
.....  
.....  
.....

10. Do you feel your needs are being met?

.....  
.....  
.....  
.....

If no, why not?

.....  
.....  
.....  
.....

11. Who are your best supporters?

.....  
.....  
.....  
.....

THANK YOU VERY MUCH FOR PARTICIPATING IN THE STUDY.

# Interview Guide - Caregivers

## Section I

1. Date of interview:  
(Day/Month/Year)

--	--	--

2. Interview number:

3. Interview code:

4. Place of interview: Home  
Health Facility  
Others


5. Age in years:

6. Gender:

F	1		
M	2		

7. Please indicate your level of education:

None	0	
Primary	1	
Secondary	2	
Tertiary	3	
Non-Formal	4	

8. Current employment status:

Unemployed	0	
Employed	1	
Self-employed	2	

9. If employed, what is your income per month?

P300-P400	0	
P400-P600	1	
P600-P800	2	
P800-P1000	3	
P1000+	4	

10. Please indicate your religious affiliation:

None	0	
Catholic	1	
Lutheran	2	
Assemblies	3	
Others( Specify)	4	

## Section II

1. How long have you been caring for the client? (Kindly indicate how many months' and/ or years).

Months	
Years	

2. Are you related to the client? Yes or No:


3. If related, how are you related?

Parent	0	
Sister	1	
Brother	2	
Daughter	3	
Other	4	

4. Tell me about the referral system in place for terminally-ill patients:

.....

.....

.....

.....

5. What are your experiences of caring for a terminally-ill patient?

.....  
.....  
.....  
.....

6. What is your perception about community home-based care programme?

.....  
.....  
.....  
.....

7. Would you advise a friend to enrol in the programme?

Yes		
No		

If no, why not?

.....  
.....  
.....  
.....

8. Please tell me about the support you receive in the community:

.....

.....

.....

.....

9. How did you come to know about this programme?

.....

.....

.....

.....

10. What do you think are the greatest needs in client care?

.....

.....

.....

.....

11. Who usually provides support?

.....

.....

.....

.....

12. What kind of support is provided?

.....  
.....  
.....  
.....

13. Can you think of any form of social support that you need and are not receiving at the moment?

.....  
.....  
.....  
.....

14. In what way can we help you?

.....  
.....  
.....  
.....

15. What do you feel about being supplied with gloves?

.....  
.....  
.....  
.....

**THANK YOU SO MUCH FOR PARTICIPATING IN THE STUDY.**