

## **CHAPTER THREE**

### **HOME BASED CARE: A LITERATURE REVIEW**

#### **INTRODUCTION**

The review explores the definition of home based care and the history of this model of care. An overview of the different home based care models is highlighted and a comparison is made of home based care and hospital care. The key aspects of managing the home based carers are discussed in relation to the COC project. It further considers the integral role of home based care in the fight against HIV/AIDS.

#### **3.1 DEFINITION OF HOME BASED CARE (HBC)**

The World Health Organization (WHO) (in Department of Health, 2001:53) defines HBC as “the provision of health services by formal and informal care givers in the patient’s home in order to promote, restore and maintain a person’s maximum level of comfort, function and health, including care, towards a dignified death”. The strength of this approach is the dignity and privacy it gives to the patient and his/her family to be cared for in the comfort of the patient’s home. However, a draw back to this approach is the likelihood of patients wanting to be cared for at home, even with conditions that are beyond the scope of care for the home based carers.

### 3.2 The history of home based care

Home based care was conceived as a means of alleviating the strain on overburdened and under-resourced hospitals whilst providing better and more holistic care to chronically ill and HIV/AIDS patients. Groups of home based carers –often drawn from churches– would visit patients in their communities, providing them with palliative and spiritual care, and educate the patients’ families on how to care for persons living with HIV/AIDS. Home based care was meant to be a *support mechanism* for the hospital system and the PLWAs and their families; a way to empower communities to respond to the impact of HIV/AIDS *themselves* by supporting them through the process (Edoh, 2004).

When there is a sick or dying person in the house, someone – quite literally - has to care, whether out of love, duty, or simply a lack of options (Ogden, et al, 2004). Indeed, research has indicated that up to 90% of illness care is provided in the home (WHO, 2002). Quite often, the burden of care is borne by women and female children (Marenga, 1995). The care work done by women and girls in the household, which includes the services associated with physical, social and psychological development of family members, as well as volunteer activities in the community that keep the social fabric in good order, is referred to in economics literature as the ‘care economy’ (Elson, 2002).

Whenever there is a household crisis, such as an illness, the amount of time and energy required to care for the person at home increases exponentially. (Ogden, et al, 2004). Depending on the nature of the crisis or illness, the duration of the increased workload can be short-or-long-term (Ogden, et al, 2004). HIV/AIDS is a chronic, long-term illness

– or in Barnett’s classification, a ‘long-wave disaster’ (Barnett, 1991; Barnett and Blaikie, 1992). According to Russel and Schneider (2000) most HIV/AIDS patients spend the better part of their illness at home. Research conducted on home and community care however suggest that there has been an increase in the number of AIDS patients being cared for in their homes as public hospitals discharge infected patients to be cared for by friends and family in line with government policies (Uys, 2001; Akintola, 2004).

Over the past few years, the largely silent epidemic of HIV has grown into a highly visible epidemic of AIDS throughout the world. As early as 1986, the Committee on a National Strategy for AIDS (CNSA) for the United States of America described the system of AIDS care in terms of three components, namely hospital care, out-patient care, and community-based care. They described the main function of each component as follows:

- **Hospitals:** Diagnosis and in-patient therapy, and discharge planning to integrate patients with out-patient and community agencies.
- **Out-patient services:** Medical management of patients with AIDS-related complex (ARC) or AIDS ideally delivered through dedicated AIDS clinics, as well as counseling and health education.
- **Community-based care:** this is care occurring at a patient’s home to support or replace hospital-based care. This includes medication management, palliative care, and social support (Committee on a National Strategy for AIDS, 1986).

Home based care programmes started in North America and Europe when it became clear that hospital care was too expensive, and that family and other carers found it difficult to cope on their own with the demanding nature of caring for people living with HIV/AIDS (PLWA) (Spier and Edwards, 1990). In the USA, the Committee on a National Strategy for AIDS (1986:101) concluded that:

“If the care of these patients is to be both comprehensive and cost effective, it must be conducted as much as possible in the community, with hospitalization only when necessary. The various requirements for the care of patients with asymptomatic HIV infection, ARC or AIDS (i.e. community-based care, out-patient care, and hospitalization) should be carefully coordinated.”

In most African countries, there are now well developed home based care programmes and systems, although access to these programmes is still not universal (Uys and Cameron, 2003).

The impact of this on health services, families and communities is placing an overwhelming burden on society at large. In an attempt to deal with this impact, it is common practice for health care facilities to rationalise services to people with HIV, and as mentioned earlier, shift the bulk of the burden of care onto the shoulders of home based carers, households and communities. No wonder that in South Africa, home based care has become a national policy priority.

Any discussion on the care and support of HIV/AIDS patients inevitably turns to the consideration of how to enlist community participation, both in minimising the impact on the formal health sector and in meeting the needs of the patients. Community mobilization becomes a key factor to sustaining the success of home based care and support programmes. Community mobilization uses deliberate, participatory processes to involve local institutions, local leaders, community groups, and members of the community to organize for collective action towards a common purpose. Community mobilization is characterized by respect for the community and its needs.

Historically, health and welfare services adopted a top-down approach where little recognition and consideration were given to the reality that communities had an inner knowledge and capabilities to develop their own resources. The AIDS pandemic has forced communities to rally together and address the challenges of the disease. Conventional methods of care and support have needed to be revisited in the light of the devastation of the disease. Clearly, the social sector leads the HIV and AIDS response. Allocations via conditional grants to the provinces prove this point. In line with the National Integrated Plan for HIV and AIDS, National Treasury has allocated HIV and AIDS funds to three social sector departments: health, education and social development. This forms the government's integrated response to the epidemic in South Africa. Budget 2005 has allocated a total of R6, 6 billion for the integrated response for the 2005/6 – 2007/8 periods (Department of Social Development Strategic Plan 2003/4 and 2005/6). It is evident that classic health services may not be able to extend their outreach to people's

homes and will be unable to address the financial and psychosocial implications of the disease on the patient and family.

Hospital-based care for the HIV/AIDS patient is, for many, out of the question. Many cannot afford the drugs or the transport costs of getting their AIDS patients regularly to the hospitals. AIDS related psychosocial interventions include: information, communication and education. These can be achieved through technological, peer, community and counseling services.

Home based care offers some solutions to the problem. It increases the involvement of the patients themselves, their families and even communities in addressing the harsh realities of caring for the infected. Traditionally, family members are regarded as the primary caregivers in most cases. Their motivations to care for their loved ones, who are ill, are obvious: they do so out of love and a sense of kinship. People dying have a need to be surrounded by those they are familiar with, and in surroundings that they are familiar with. This affords them with the control of reliving past memories and addressing unresolved issues in the familiarity of their homes. Palliative care has been defined as the combination of active and compassionate long-term therapies intended to comfort and support individuals and families living with a life threatening illness. It aims to improve the quality of life at the end of life by relieving symptoms (especially pain) and enabling people to die in peace with dignity and in keeping with their wishes (WHO, 2002). The focus of home- based palliative care for the dying patient largely fulfills the patient's and family's needs.

According to the National Guidelines on Home Based Care and Community-Based Care, Department of Health (DOH), 2001, home care services can be classified into preventive, promotive, therapeutic, rehabilitative, long term maintenance and palliative care categories. Community-based care is the care that the consumer can access nearest to home, which encourages participation by people, responds to the needs of people, encourages traditional community life and creates responsibilities (DOH, 2001). These patient- and family-centered approaches use the skills of interdisciplinary team members to provide a comprehensive continuum of care including spiritual and emotional care (WHO, 2001).

Additionally, families are an ideal entry point for educational messages about HIV/AIDS prevention in communities. Community volunteers or home based carers have partly filled this gap by participating in home-based care. Experiences from the Community Outreach Centre, St Mary's (COC) in Mariannhill, Kwa Zulu Natal, show that home based carers, under the supervision of experienced nurses, can be an efficient and effective means to extending services to the neediest.

Recent developments in disease and illness management show the value of home based care in dealing with the issues that HIV/AIDS raises. Some of these issues are: procurement of high quality male and female condoms; Sexually Transmitted Illness (STI) management; life skills and HIV/AIDS education; Tuberculosis control and integration with HIV/AIDS; prevention of mother-to-child HIV transmission (PMTCT); vaccine development; and blood safety.

In many instances home based carers are leading the communities' responses in prevention and care initiatives. Far from becoming incapacitated victims of HIV/AIDS and poverty themselves, their resilience is inspiring. NGOs and Faith Based Organizations (FBOs) have a very important and leading role to play in bringing about changes in the way in which home based carers are treated.

The role of home based carer can be seen as:

- Care that is based outside the conventional health care facilities (hospitals, hospices, health centres) but has some connection with the formal health and welfare sectors;
- Care that addresses any aspect of 'continuum of care and support', from the time of infection to death and to the psychosocial and economic impact on the survivors.

The ultimate goal of HBC is to provide hope through high-quality and appropriate care to assist ill people and their families to maintain their independence and achieve the best quality of life in the comfort and familiarity of their own homes. Home based care structures offer home based carers training on how to care for patients in a variety of ways. They train home based carers to counsel patients and their families, help to monitor medication needs, teach the primary caregivers about symptomatic treatment and monitor the needs of the children in these homes. One of the most lasting benefits of home based care is the way in which it reduces the stigma surrounding HIV/AIDS, as the community



sees the way these home based carers touch and care for those who are infected by HIV/AIDS. Seeing other members of their society valuing the lives of those who are ill changes perceptions of whole communities (DOH, 2002). The home based carers' attitudes towards their patients empowers the community to address its misconceptions and prejudices about HIV/AIDS, making the community less scared and less inclined to reject those infected by the disease. The World Health Organization (2001) suggests the need to develop a structured approach to home based care that involves beneficiaries and their families, as well as communities.

Home based care may not be the ultimate answer to care for the HIV/AIDS patient or other chronic illness. However, it offers an alternative to:

- Clinic based care for those who suffer from chronic or terminal illnesses;
- Those who cannot afford clinic based care; or
- Those who prefer being treated and taken care of in their natural, familiar environment.

Home based care may well be a viable solution to providing for basic needs of the chronically ill, in environments where resources are constrained. Home based care assures high quality of care whilst at the same time conscientises families and communities to the pivotal role they have to play in the fight against the pandemic of HIV/AIDS. Well-organized and well-funded home based care programmes may provide basic care to those who cannot seek clinical care because they cannot access it for

different reasons. Some of these reasons could be the lack of funds to transport patients to hospitals or clinics; the long distance that patients have to travel to get to health institutions; and the compromised position some health institutions find themselves in, as a result of having to cope with the influx of patients.

Through its participatory approach involving and sensitizing a broad spectrum of community members, home based care may provide an opportunity for the alleviation of stigma that People Living with AIDS (PLWA) are confronted with. By openly and freely caring for PLWAs, the home based care send a clear message that HIV is not transmitted by the simple act of caring for a person. Home based carers also send a clear message that PLWAs are not ‘social lepers’ that must be ostracized and banished from the mainstream of the community but rather that with care, love, support and understanding, PLWAs can be integrated into families and communities as functional, contributing members.

### **3.3 MODELS OF HOME BASED CARE**

Thus far, most home based care services have been established through unsystematic, needs-based efforts (Uys and Cameron, 2003). As the HIV/AIDS pandemic continues to grow, many organizations and communities recognize the need to expand in a more pragmatic manner. Countries are looking for ‘scaled-up’ responses and national strategies for home based care. A key to this is to understand what home based carers dealing with HIV/AIDS really need, to keep them engaged in these programmes. It is expensive to

provide the basic training in home based care and management of a HIV/AIDS patient; so therefore, it is a critical objective to reduce the dropout rate of the home based carers. Home based Care organizations recognize the importance of providing home based carers with adequate training.

These trainings should include:

- General basic nursing care
- Training primary caregivers in home based care
- Counseling services of patients and families
- Assessments of basic needs (food, shelter, clothes etc)

It has given little or no attention to researching their needs and ways of sustaining their involvement in volunteer capacities. The time has come for home based care services to develop empirically validated programmes for home based carers that fulfill their needs so that they will continue to provide meaningful services to HIV/AIDS sufferers and their families, in their own communities.

A number of different systems on home based care have been reported on in the literature namely Uys and Cameron (2003); Loudon (1999); and Defilippi (2005):

### **3.3.1 Integrated home based care**

This model works by linking all service providers with patients and their families in a continuum of care. The aim is to enhance mutual support between the different systems: patient, family, home based carer, hospital, clinic, and NGO. This system allows for referral between all partners as trust and capacities among these partners develop. The patient and family are the focus of the care and support. The small group is supported by a larger network of services (home based carers, clinics, hospital), and the larger community (Uys and Cameron, 2003). The care given is based on home based care and palliative care standards. Its primary purpose is the prevention of illness, and related complications, by increasing openness and understanding among participants, hereby changing behaviour (Louden, 1999). The research facilitator believes that an additional motivation for this model is its emphasis on support. Open support of the HIV positive patient and family encourages people to better understand the disease and makes them open to learning new skills about how to control and manage it.

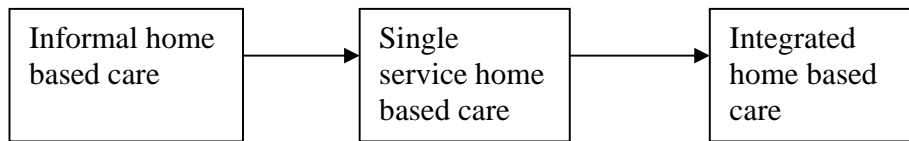
### **3.3.2 Single service home based care**

In this model, one service provider (a hospital, a clinic, a NGO, or a FBO) organizes home based care by recruiting volunteers, training them, and linking them to patients and their families at home (Uys and Cameron, 2003). While this is largely how most home based care initiatives started out, it soon became evident that networking with other stakeholders was crucial if the intention was to provide holistic and adequate home based care.

### **3.3.3 Informal home based care**

In this model, families are helped to care for their sick members in their own homes, with the informal assistance of their own social network. Nobody has any specific training or external support, and there is no structured or organized intervention (Uys and Cameron, 2003). This model held true during the pre HIV/AIDS era. Since the onset of the disease, it has become increasingly important that home based care becomes more formalized and organized.

The ideal would be if all home based care could be delivered via the integrated model. This model ensures that the patient and family receive all the care and support they need from the point of diagnosis through to terminal care. Support is made available to the families when the patient dies. This model ensures that the quality of care is optimal, since there is regular supervision and support from the home based carers and the 'employing' NGO/FBO who strive to improve care. Because this model relies on high levels of recruitment and involvement we witness the single service home based care model more frequently being used and this will continue until more partners can be recruited and formal structures are put in place. Informal home based care is very strenuous because those home based carers have to deal with the burden of lack of necessary skills, training, knowledge and emotional tenacity to care and support their patients. The models may be viewed as a progressive continuum of care process as outlined below.



**Figure 1: Progressive continuum of care process**

The challenges facing the progressive continuum of care process are as follows:

- Often, informal care may be the beginning and end of the continuum of care process. Accessing health facilities is difficult due to a lack of transport/funds to get to institutions, or even a lack of awareness of the existence of such institutions. In such instances, the families are expected to rally together, as best as they can, to care for the patient - often in the process exposing himself or herself to the virus.
- As discussed earlier, single service home based care services such as hospital outreach programmes and clinics, are finding it increasingly difficult to cope with the flood of desperate patients trying to access their services. Many such institutions are being forced to impose a cut-off quota for the day, such as shutting their doors after the first 150 patients have been registered. Addington Provincial Hospital, in Durban, and the R.K.Khan Provincial Hospital in Chatsworth are two such hospitals that have been forced to adopt a similar stance to cope (The Rising Sun, 2005). This is the last resort that health care institutions are exploring and adopting, but as they cannot meet the demands for their services, patients rely

more and more on their families and communities to care for them. The family often carries the burden of care.

- Integrated home based care poses many challenges even though it is largely viewed as the ideal model. This model relies heavily on trust that the other ‘partners’ will provide their services adequately and effectively and that networking will be an ongoing process among the different systems. Most home based care organizations/systems are governed by their own constitution, values and policies. While all have one common aim: the home based care and support of the patient and the family, trying to synchronize these efforts remains a challenge.

### **3.4. HOSPITAL- BASED CARE VERSUS HOME-BASED CARE IN TREATING PEOPLE LIVING WITH HIV/AIDS**

There are two ways of caring for people living with AIDS: hospital-based care and home based care. As mentioned hospital-based care fails to cope with the overwhelming number of patients suffering from HIV/AIDS, at a time when there has been an increase in the exodus of medical staff overseas. Hospitals and other health facilities are overburdened because they are either short staffed or staffed with inexperienced members. As hospital –based care is unable to deal with the scourge of HIV/AIDS, the second option: home based care, has become more prominent.

**Table 1: Comparisons between hospital-based care and home based care (Beechey, J. 2004:76).**

<b>Hospital-Based Care</b>	<b>Home-Based Care</b>
High costs to set up and run	Low cost in comparison to hospitals
Focus of care is on the disease	Focus is the whole person
Quality of medical care is good	Quality of medical care is good
Non-medical care is not available	Non-medical care is available
Relationships exists with medical staff only	The patient is part of a web of relationships including medical staff, volunteers, community and other HIV positive people
Awareness and prevention are regarded as separate activities	Awareness and prevention are integrated
Patients are referred to outside organizations to access long-term, holistic care	Patients are helped to access hospital treatment when needed

This table reveals that there are many positive indicators why home based care is an attractive alternative. Rather than just visiting a hospital for treatment, a HIV positive person becomes part of a network of caring relationships. These networks support them medically, as well as provide socio-emotional support, whilst simultaneously encouraging the patients and their families to remain healthy. Home based care facilities develop links between the HIV positive patients and their families, with other people living with HIV/AIDS who understand what it means to be HIV positive. Care and support is holistic and inclusive because the patient is cared for physically, emotionally, spiritually and socially cared for by trained home based carers with the aim of healing



their bodies and souls. Hospitals are finding it increasingly difficult to provide such holistic support. A holistic approach is particularly important in a disease that may last for many years and has such wide-ranging social ramifications. Perhaps the most important difference between hospital and home based care is the support groups that arise out of this care – both for the patients and the home based carers.

Support groups popularity is grounded in the fact that the existing health institutions networks continues to leave a gap of unmet psychosocial needs. These unmet needs can often be alleviated by mutual aid provided by people who share a common experience. Mutual aid complements professional help by adding a dimension of support that is best provided by other members of the group in need. Themes of discussion in support groups include the emotional impact of illness, the meaning of illness, family difficulty, and problems of intimacy, sense of isolation/stigma, role changes, and cancer-specific concerns.

### **3.5 BENEFITS OF HOME- BASED CARE FOR PEOPLE WITH HIV/AIDS**

As discussed by Uys and Cameron (2003), the benefits of home based care may be summarized as follows:

- It affords the patient and the family time to come to grips with the illness, and the impending death of the patient.
- It is less expensive for the family because problems with transport to the hospitals/clinics, time spent on hospital visits, and other related costs are reduced. Relatives can care for the patient while doing other chores.

- Care is more personalized, and the patient is likely to feel less isolated from family and friends.
- People prefer to face ill health and death in familiar surroundings rather than a clinical hospital ward.
- Home based care is less expensive for the country than institutional options (hospitals, hospices) since periods of stay at those institutions are reduced.

### **3.6 KEY ASPECTS OF MANAGING HOME BASED CARERS**

Key aspects that require special attention when managing home based carers include: motivation, special needs of home base carers, recruitment and selection of home based carers, training of home based carers, and the retention of home based carers.

#### **3.6.1 Motivations of home based carers caring for PLWAs**

It can be argued that volunteering demands a relatively high level of commitment from individuals. It is much easier to write a cheque for charity than to devote hours, or even days, of one's time to volunteering. Yet charitable organizations and NGOs depend on volunteer efforts as much as they do on funds. Therefore, understanding motivations and expectations as they relate to volunteering, may ultimately help organizations make the adjustments that allow them to sustain a stronger, and longer serving, volunteer base.

Akintola (2004) describes 7 broad factors that motivate home based carers to volunteer in care activities. They are:

- ***Pure altruism:*** UNAIDS (2000) notes that there is a strong sense of community and a rich tradition of doing community work and reaching out to one's neighbour or sick friend in Africa. Because people are dying in large numbers in communities, it is difficult for us to ignore. Members of communities, who are compassionate, see volunteering as a way of contributing their own quota to solving common problems that are currently bedeviling their communities. Most caregivers mentioned their love and empathy for the sick as their primary reason for becoming volunteers. They try to place themselves in the shoes of the sick (Akintola, 2004).
- ***Unemployment:*** Lack of employment is a common denominator among people who have volunteered to be caregivers. Most home based carers apply to participate in the programme because, in addition to other motivations, they do not have any work and have time to spare. Some mention the fact that they do not want to stay home doing nothing since it is not healthy to do so. They decide to engage in something that is productive whilst they continue their job search. Many, however, find that they became so emotionally involved in care giving that it is difficult to quit even when they find employment (Akintola, 2004).
- ***Hope of future reward and reciprocity:*** The hope of future reward was a pervasive theme given by home based carers for volunteering. Some home based carers see volunteering as 'sowing a seed that will later be rewarded'. They believed that they will be cared for if they ever have similar needs in the future.

Some volunteers state that the hope for some sort of reward from the government is one of the motivations for giving care. Although in most cases this is not a primary reason it as an underlying wish (Akintola, 2004).

- ***Religious considerations:*** There are also religious considerations in volunteering as caregivers. Some volunteers indicate that it is godly to volunteer (Akintola, 2004). There is a common belief among some that volunteering is synonymous to doing God's work. They see their role as home based carer as an enactment in the image of God, therefore giving them a closer link to Him.
- ***Experience of HIV/AIDS in the family:*** Many of the home based carers experience HIV/AIDS in their households and therefore feel the need to acquire skills to deal with the situation. Some of the people who enroll as home based carers recognize the need to give adequate supportive care to HIV/AIDS patients, because of the chronic nature of the disease, and the complex nature of the activities that are required to care properly for the sick. Some volunteers experience multiple illnesses in their families and believe that if they are trained to care for the sick it will be of great help to them in dealing with their own families (Akintola, 2004).
- ***Previous experience or interest in paramedic or community work:*** Experience with medical or paramedical work is a motivating factor among home based carers. A study by Uys (2001) reports that many of the subjects in her study of

home-based care of the Department of Health in the seven pilot sites in South Africa, had previous experience in community or paramedic work. This might be due to the fact that the home-based care model evaluated by Uys required that one have a previous experience with community care as one of the criteria for recruitment into the programme (Akintola, 2004).

- ***Hope of securing employment:*** As noted by UNAIDS (2000) the hope of securing a job is a covert reason for people to volunteer as home based carers. While home based carers do not make this explicit; this information was not readily given by any of them. Some studies indicate that some ‘volunteer’ home based carers receive some form of stipend to cover some of their expenses (UNAIDS, 2000; Uys, 2001). Instead, and in the absence of funds, volunteers occasionally receive incentives like biscuits, soaps, and cosmetics among others, which have been donated to the programme (Akintola, 2004). This satisfies their material needs to some degree.

As discussed earlier, there is a paucity of literature on the motivations and expectations of home based carers caring for HIV/AIDS patients. In the absence of the desired empirical evidence, the research facilitator interviewed four project managers and staff of home based care organizations to establish what perceptions they had about the motivations of their home based carers. These organizations were: Sinosiso Home Based Care Programme, The Dream Center, Hope and Family Life Foundation, and St Clements Home Based Care Programme.

No formal research had been conducted into the needs, motivations and expectations of their home based carers at any of these organizations. The information gleaned was from the project managers' and staff's personal observations and their informal discussions held with their home based carers, that they had gathered over a period of time. The following organizations were interviewed:

- ***Sinosiso Home Based Care and Orphan and Vulnerable Children Programme*** – situated in Amanzimtoti, south of Durban, it provides free home care services to people living with HIV/AIDS and their families. It also provides outreach to chronically ill and aged clients in the community. Sinosiso means “We Help” in Zulu. This programme offers Home Based Care Service, Orphan Care, Training, and Anti Retroviral Clinic Services. The Catholic Archdiocese of Durban AIDS Care Commission (CADACC) coordinates the project.
- ***The Dream Centre*** - a ‘step down’ facility for HIV/AIDS patients, situated in Pinetown, east of Durban. A ‘step-down’ facility, in the context of the health setting, can be described as a non-hospital based continuum of care facility for the HIV positive patient. It encourages family intervention and support. The Dream Centre is a Section 21 company, registered under the name of the Mophela Housing Trust. It operates as a mission/outreach in association with Ambassadors for Christ, Canada. It is a NGO facility that provides institutionalized home based care for the non-hospital based continuum of care for HIV/AIDS patients, and terminal or Palliative Care for HIV/AIDS patients.

- ***Hope and Family Life Foundation*** – is recognized as a capacity building organization, which is situated in Mariannhill, east of Durban. The church, in response to the breakdown of family life, started this initiative. This NGO promotes healthy Christian family life that upholds the dignity of life and empowers individuals, families and communities through counseling, education, training and development. Two programmes drive this organization: their HIV/AIDS Desk and the Children’s Centre.
- ***St Clements Home Based Care Project*** – offers a home based care programme in Clermont/Kwa-Dabeka district, north of Durban. This project renders supportive services to people affected/infected by HIV/AIDS. Service delivery includes: home based care, the distribution of food parcels, a meals-on-wheels scheme, and services to Orphan and Vulnerable Children.

The research facilitator conducted twelve interviews over a period of one year with the aforementioned project managers and staff, using semi-structured interviews. While the common themes cited were grouped together and are presented below, the themes that emerged have been further consolidated in Chapter Six.

- ***Empowerment:*** Training and skills acquisition empower the home based carers to volunteer. Being unskilled, home based carers are anxious to secure any opportunity to be trained.

- ***Personal experience with death and illness:*** Many home based carers have either lost a loved one to HIV/AIDS or have a loved one infected by the disease. Joining a home based care organization seems to offer them renewed hope and helps them to work through their experiences of hopelessness.
- ***Religious reasons:*** All of the organizations that were interviewed are faith-based and a strong Christian ethos predominates in each of them. The home based carers have strong Christian backgrounds steeped in African tradition. They believe that doing good to others will in turn bring good upon themselves and their off spring. Interestingly, a similar finding was made in this study as can be read in Chapter Six. A strong sense of Ubuntu (spirit of care and support) predominated.
- ***Hope of employment:*** Some home based carers hope to secure employment as a direct result of the training they receive from their respective organizations. When home based carers manage to secure employment, the home based carers who are left behind see this as something to aspire towards and their hope is renewed. Most hope to be employed by the organization where they volunteer.

It is hoped that the research undertaken would offer empirical validity to the observations of the service providers.

An understanding of home based carers' motivations for volunteering is critical to understanding their role in mitigating the burden of caring for people living with



HIV/AIDS (Akintola, 2004). Although many of them are unemployed and themselves living in poverty, they are generally driven by magnanimity and the will to make the lives of their patients better. They carry out their work with a sense of commitment and dedication earnestly seeking to end the misery of community members. In the process they often confront other problems that complicate their lives and that of their families. Indeed these volunteers constitute the backbone of the home based care programmes/projects. They are an invaluable resource to affected households, communities as well as the health care system. A strong theme that emerged from these interviews was that there are no formally agreed upon measures in place to motivate home based carers – this is done informally and varies from organization to organization (Akintola, 2005).

### **3.6.2 Individual needs of home based carers**

All volunteers have their individual needs that motivate them to volunteer. Similarly, all organizations, including NGOs, identify particular areas of work for home based cares in an effort to attempt to ensure that their needs are met. Fisher and Cole (1993) indicate that organizations wishing to attract and retain volunteers need to be sensitive to the needs that are dominant among those they seek. Psychological needs influence individuals to participate in volunteer activities. As summarized earlier in the chapter, the needs of each individual volunteer may vary, but from literature, the following general needs of volunteers are identified: the need for personal satisfaction and recognition; personal contact; good quality training; the need for accomplishment; doing good or helping those less fortunate; an opportunity to learn and develop new skills; and

expression of ones social and religious commitment. Some of these needs will be discussed in the context of the COC setting.

- ***Personal satisfaction and recognition*** – COC recognizes this unselfish, noble gesture of serving their people and community by providing incentives to the home based carers and awarding them with certificates at the end of their trainings. Some of the incentives are: edibles like biscuits; food vouchers; sanitary pads; free medical treatment at the St Mary’s Hospital. The Hope and Family Life Foundation provide their home based carers with transport fees and meals for the days when trainings are provided. Sinosizo Home Based Care and Orphan and Vulnerable Children’s Programme also offers a similar incentive scheme as above.
- ***Training*** – the COC recognizes the need for good quality training and as such has a structured training curriculum that home based carers are trained in.
- ***Personal contact*** – following close on the need for personal satisfaction, the home based carers value the contact they have with the patients and the help that they bring to them. They also value the contact they have with the organization, the manager, the staff and other volunteers of the organization.

Understanding the needs of the home based carers, and the needs of the COC, plays an important part in the recruitment and retention of the home based carers at COC.

### **3.6.3 Recruitment and selection of home based carers**

As outlined in Chapter Two, Lauffer and Gorodezky (1977) state that recruitment requires more than just “putting the word out” – it requires having systems in place to effectively manage the volunteers. Home based carers need to be carefully screened and recruited into care giving programmes. Home based care organizations often utilize a whole day in the careful screening of prospective home based carers. This is to ensure that as far as possible the prospective home based carers are aware of what the tasks entails and the organization feels confident in investing its time and resources in upgrading the home based carer. Ultimately, the continuity of uninterrupted service delivery to patients is paramount.

### **3.6.4 Training of home based carers**

Training home based carers is essential if they are expected to provide good, quality care. Most organizations utilizing home based carers have, in place, a training schedule. While the training modules may differ among organizations with regard to the numbers of courses offered and the duration of the courses, all home based care training focuses on teaching basic nursing skills, and emphasizes the practical care of the patient in the home. The COC has a training curriculum that is compulsory for every home based carer to be trained in. The COC also has optional, specialized training opportunities, for example, Palliative Care and Child Care, that home based carers are selected to undergo, based on their performance and skills while in the programme. The COC also provides refresher training courses and in- service training (COC Fact Book, 2005). The aim of the training

offered by the COC is to ensure that the home based carers are skilled and knowledgeable in the care of their patients and that they, as volunteers, are empowered and capacitated to upgrade and eventually seek formal employment.

### **3.6.5 Retention of home based carers**

In any organization, management wants to retain volunteers, especially when much time, money and resources has been invested in recruitment and training. Currently, the COC has 352 trained and active volunteers in its programme, 40% of whom have been volunteers for five year and more (COC Fact Book, 2005). In 2004, 49 volunteers left the COC to take up formal employment – some at COC itself, some at the St Mary's Hospital, and the rest elsewhere. Interestingly, most of them still continue to volunteer as home based carers in their spare time (COC Fact Book, 2005).

## **SUMMARY**

There are currently still thousands of PLWAs, and their families, who are not being cared for by a dedicated home based care team. Where such programmes have been implemented and evaluated, PLWAs and their caregivers, as well as health service providers, are all convinced of their intrinsic value (Uys, 2001). Clearly, a need exists for more services like those to be set up. This is not one organization's task, but the responsibility of every community and service provider (Uys and Cameron, 2003).

The literature review presents a working definition of the term 'home based care' and looks at the history of home based care. The literature also describes the three models of home based care: integrated home base care, single service home based care, and informal home based care. The reviewed literature provides a comparison between hospital-based care and home-based care in treating PLWAs. The literature also highlights the benefits of home based care with particular emphasis on the personalized nature of care, and the cost effectiveness of care, that only home based care can offer.

Key aspects of managing home based carers were discussed and the literature reviewed provided one with a comprehensive understanding of the intrinsic motivational factors, needs, and expectations of volunteers providing home based care. Intrinsic motivational factors were described as: pure altruism, unemployment, hope for future reward and reciprocity, religious considerations, personal experiences of HIV/AIDS in the family, previous nursing or paramedical experiences, hope of securing employment, empowerment, and personal experiences of death and illness in families. Needs of home based cares were described as the need for personal satisfaction and recognition; personal contact; good quality training; the need for accomplishment; doing good or helping those less fortunate; an opportunity to learn and develop new skills; and expression of ones social and religious commitment. The review ended with a discussion on the recruitment and selection, training, and retention of home based carers as key aspect in the effective management of home based carers.

The review showed that despite the acknowledgement in the literature of the importance, and the value of the home based carer in the step-down care of HIV positive patients, very little locally specific research is available on the motivations and expectations of home based carers. While there is an abundance of literature focusing on the impact of HIV/AIDS on the government and communities, this review has shown that much of it has been drawn from anecdotal sources. Why this has arisen is not clear. Stein (2003) suggests that perhaps the speed and magnitude of the HIV/AIDS pandemic justifies the use of untested theories. Clearly, there is a need for a greater body of scientific evidence on home based carers' motivations and expectations.

While Akintola (2004) provides a useful guide to understanding the motivations of family care givers, his research failed to differentiate family care givers from home based carers. It is acknowledged that while family care givers could also be home based carers, and vice versa, it is very important to make this distinction, as the level of emotional involvement in the care of a family member will invariably be greater than the emotional involvement in the care of an unrelated patient. Consequently, the motivational factors to voluntarily care would also be affected.

Akintola's (2004) research failed to reflect the specific profile of the larger Mariannahill region's home based carers and just concentrated on two communities in Ward Seventeen of Mariannahill. The unique characteristic of the Mariannahill region, and its dwellers, was not fully captured as a result of this confinement, and therefore, generalizations cannot be made on the Mariannahill region and its dwellers.

Sadly, not much locally specific literature on home based care, and in particular on the motivations, needs and expectations of local home based carers, was available. Having largely used Euro centric literature, its relevance to the African setting is contentious. However, with HIV/AIDS being a global issue, and with most countries struggling to cope and contain this pandemic, the literature lends support and credibility to the different and unique models of home based care developed in an attempt to best deal with this global crisis.

The response from the communities and families to alleviate the impact of HIV/AIDS on the care of the patients has been forthcoming. NGOs, CBOs, and FBOs have also responded with a wide range of impacting programmes on home based care and support (Uys and Cameron, 2003). There seems to be no doubt that volunteer/home based care mobilization seems to be the backbone of NGOs, CBOs, and FBOs (Edoh, 2004). Consequently, there needs to be more formal and scientific evaluations to assess home based carers' motivations and expectations in their roles as volunteer, giving way for the need for further study in this regard.