

CHAPTER 2

LITERATURE REVIEW

2.1. INTRODUCTION

This chapter reviews some of the literature pertaining to the many salient and prominent issues within the area of HIV/AIDS and Home Based Care. The nature of Home-Based Care will initially be defined and discussed, followed by ascertaining the types of services they offer, and who the primary beneficiaries of the Home Based Care should entail. The identified psychological and emotional needs of the beneficiaries utilizing the services will then be discussed, followed by a look at the role of home-based caregivers, the services offered by Home Based Care, and the types of psychological and counselling services that home-based caregivers both offer and receive within Home Based Care programmes. Finally, the training that home-based caregivers receive will be examined, and some of the more general benefits and challenges facing contemporary Home Based Care Programmes discussed.

2.2. THE HIV/AIDS PANDEMIC: A CALL FOR DRASTIC AND DIVERSE MEASURERS

“This disease has not spared anyone or any area of our district. It has taken a holistic approach” (Community Development Worker, Oxfam GB Malawi Case Study, 2001, p. 189, as cited in Holden, 2003, p. 9).

2.2.1. Historical Background to HIV/AIDS

The first reported cases of the Acquired Immune Deficiency Syndrome occurred in America in 1981, when a very rare form of pneumonia suddenly appeared in several patients simultaneously (van Dyk, 2001). These patients had a number of common characteristics, for example they were all young homosexual males with compromised immune systems (Adler 1988, as cited in van Dyk, 2001). Not long afterwards, a new disease which undermined the immune system and caused diarrhoea and weight loss, was identified in Central Africa in heterosexual patients. It was not until 1983 that it was discovered that the disease was caused

by a virus, which at that stage was known as LAV (Lymphadenopathy-Associated Virus) and HTVLV-III (Human T Cell Lymphotropic Virus Type III). In May 1986 the virus was renamed HIV (human immunodeficiency virus) (Holden, 2003; van Dyk, 2001).

2.2.2. A Global Pandemic

The HIV-infection has become a global pandemic and phenomenon, with reported cases in every country (Barnett & Whiteside, 2002). However, the disease is evidently not spread evenly. Sub-Saharan Africa is thought to house “70 per cent of the total number of people of all ages infected with HIV, while the less developed countries together account for more than 90 per cent of the world’s 42 million HIV-positive people” (Holden, 2003, p. 12). Deaths from AIDS are even more prevalent in the poorer nations, with less developed nations thought to account for 98 per cent of the world’s AIDS deaths in 2002 (UNAIDS, 2002). Furthermore, UNAIDS predicts, that without extensive and rigorous prevention efforts, an extra “45 million people are expected to become infected with HIV in the less developed countries by 2010” (UNAIDS, 2002, p. 5).

In South Africa specifically, the HIV/AIDS epidemic is serious and widespread (Shisana & Simbayi, 2002). According to the Population Reference Bureau (2002, as cited in Department of Social Development, 2002) in 2002, nearly 5 million of the population in South Africa were infected with HIV, the highest number in any country in Africa. The impact that this is having on hospitals, families, and communities is evidently dramatic and very serious. Resources are becoming even more depleted and scarce than before, and formal institutions are just not coping (Russel & Schneider, 2000). Limited resources have forced formal health care services to ration services and resources, and on some occasions to be discriminatory in terms of who can and cannot receive health care. Thus even if hospital or other institutional care is deemed to be the required discourse for treatment, it may not necessarily be available.

It is also apparent that not only has HIV/AIDS resulted in an increase in the incident of disease in general, but the need for a continuum of care has also emerged. The progression of HIV to AIDS can vary from anything from a few months to more than a decade, and the advanced stages of HIV are chronic, with patients experiencing periods of relative health between relapses triggered by opportunistic infections (Department of Health, 2002). This too

is increasing the pressure and burden placed on hospitals and institutional care, as well as families and communities in general (Department of Health, 2001; 2002).

2.2.3. Alternatives: Where To From Here

As early as 1986 the Committee on a National Strategy for AIDS (CNSA) described the system of AIDS care essentially in three components, namely hospital care, out-patient care, and Home Based Care (Uys, 2003). According to the CNSA (1986, as cited in Uys 2003, p. 3) the main functions of each component should be as follows:

- *Hospitals:* Diagnosis and in-patient/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 Acquired Immune Deficiency Syndrome (AIDS), ideally delivered through dedicated AIDS clinics, as well as counselling and health education.
- *Home Based Care:* This is care occurring at a patient/patient's residence to supplement or replace hospital-based care. This includes medication management (including infusions), palliative care, and social support (counselling)

Hence, Home Based Care, which essentially began in America, developed out of the direct realization that institutional and hospital care was becoming too expensive and overloaded, and that families and communities were finding it too difficult to cope on their own with the demanding care of people living with HIV/AIDS. It was concluded therefore that if care for these patients is to be comprehensive and cost effective, it must be conducted as much as possible within the community, with hospitalization only when absolutely necessary. Home Based Care essentially offers a potential solution to these problems, both alleviating institutional health care facilities and offering a continuum of care to patients (Ross, Greenfield & Bennett, 1999; Russel & Schneider, 2000).

2.3. DEFINING HOME BASED CARE

“Home-based care is taking us back to the root of human coexistence. It reminds us that we all have a responsibility to one another. If we hold hands through this tragedy...we will be

able to retain our humanity and will come out of this epidemic as a stronger community.”
(Joy Phumaphi, Minister of Health, Botswana, as cited in WHO, 2003)

2.3.1. General Overview

According to the World Health Organization (WHO, 2001), *home-based care* refers to the provision of health services by formal and informal caregivers within the home. The aim of home-based care is ultimately to “promote, restore and maintain a person’s maximum level of comfort, function and health, including care towards a dignified death” (Department of Health, 2001, p. 1). The WHO (2003) foresees home-based care as an integral and integrated aspect of *Based care*. Based care is defined as the care that the health consumer (beneficiary) can “access nearest to home, which engages participation by people, responds to the needs of people, encourages traditional community life and creates responsibilities” (Department of Health, 2001, p. 1).

In essence then Home Based Care can be considered as an alternative to traditional institutionalized care, focusing on palliative care in the home. Palliative care refers to the “active, total care of a patient whose disease is not responsive to curative treatment” (Department of Health, 2002, p. 1). It should not be viewed however as “second class care” or “cheap care” for those who are unable to afford institutional or hospital care. Instead it should be seen as a means to effectively treating commonly occurring diseases and illnesses within the home, which do not necessarily require institutionalized care (Department of Health, 2001). Russel and Schneider (2000, p. 3) summarize Home Based Care and support as “all activities that are based outside conventional health facilities (hospitals, clinics, health centres) but which have linkages with the formal health and welfare sector” and which “addresses any aspect of the continuum of care and support, from the time of infection through to death and impact on survivors”. Home Based Care therefore is ultimately any form of care given to the sick within their home (WHO, 2002). However, it should be noted that although they aim to provide care to the sick within their home, the patients that are being dealt with by Home Based Care models predominantly are HIV/AIDS patients (Department of Health, 2001; Uys, 2003; Gwyther & Marston, 2003).

2.3.2. The General Principles Of Home Based Care

Home Based Care models in general adopt a *holistic* approach to care (Department of Health, 2001). Physical, social, psychological and emotional, economic and spiritual factors are all taken in to account and considered collaboratively with, and within the community setting (Defilippi, 2003). Communities need to be integrated into the existing system/s (Department of Health, 2001). Home Based Care models are also generally *person- centred* and *comprehensive* (Department of Health, 2001). They aim to take in to account factors such as culture, religion, and values systems, and respect people's rights to privacy and dignity, which fits in well with its "community-driven" philosophy (Department of Health, 2001, p. 4). They are comprehensive and all-encompassing in terms of being preventative, promotive, therapeutic, rehabilitative and palliative (Anonymous, 2003; Department of Health, 2001). Multi-sectoral involvement and interdepartmental involvement is therefore strongly encouraged.

Home Based Care models aim to empower communities, thereby promoting autonomy and functional independence (Department of Health, 2001). Comprehensive access to health care is promoted, covering the total life span. Cognizance and recognition to diversity is also promoted. Finally, Home Based Care models also aim to offer basic and essential components of primary health care, adhering to basic principles in health care and development (Defilippi, 2003).

2.4. THE STRUCTURE OF HOME BASED CARE

According to the Department of Health (2001; 2000) the generic roles and structure of Home Based Care will differ according to the model of service adopted. In general terms Home Based Care is comprised of various disciplines from the formal, non-formal, informal and private sectors (Department of Social Development, 2003; Department of Health, 2001; 2002). The formal sector includes doctors, nurses, psychologists and social workers. Their primary focus includes consumerism, coordination, planning, evaluation, training, management, policy development and system support. The non-formal sector includes Non-Governmental Organizations (NGOs), Based Organizations (CBOs), Faith-Based Organizations (FBOs) and traditional healers. They all work closely with the community,

identifying needs, resources, services, quality of care and consumer satisfaction. They also advise the formal sector, negotiating and lobbying for services and resources (Department of Health, 2001). The informal sector includes community health workers, families, volunteers and home-based caregivers. Their objectives generally are to provide preventative care, emergency and basic care, psychological support, rehabilitation, health promotion and education, referrals and household assistance (Department of Social Development, 2003; Department of Health, 2001). Finally the private sector serves to encourage medical aid schemes to contribute to the cost of Home Based Care and to identify gaps in the provision of health care services (Department of Health, 2001).

Home Based Care is usually based outside formal health facilities, but is built in *partnership* with formal government sectors and non-formal sectors. According to the Department of Health (2001), Home Based Care cannot be accomplished successfully by only one sector of society working in isolation from the others. The support of members from other sectors, such as education, social development, local government, traditional healers, FBOs, NGOs and CBOs, are all vitally important in ensuring the success of Home Based Care within South Africa and the provision of a 'continuum of care' (Russel & Schneider, 2000). Home Based Care requires the resources, skills, time, energy and funds of both communities and governments. Resources need to be utilized effectively and referral linkages made between all sectors appropriately (Russel & Schneider, 2000). No single entity or sector is capable of meeting the total requirements and challenges of Home Based Care on its own. A collaborative effort is therefore essential for success. "Care in the community must become care by the community" (Department of Health, 2001, p. 1)

2.5. SERVICES PROVIDED BY HOME BASED CARE

Home Based Care models essentially aim to empower individuals and communities, ensuring access to comprehensive services and support (Department of Health, 2001). The primary services provided by Home Based Care models include: *medical/nursing service*, *social services* and *counselling services*. The Medical/ Nursing services provided involves complementary support services in hospitals, outsourcing nurses for home-based care, training, referrals, primary health care (preventative care) and palliative care to name but a few (Department of Health, 2001). The social services provided include financial and

material support, such as food parcels, as well as legal advice. Medical, legal and, or social referrals within the community are also often elicited at this level (Russel & Schneider, 2000). Finally, the counselling services provided within Home Based Care include for example, bereavement counselling, one-on-one counselling, family and groups therapy (support groups), general psychological support, and psycho-education, all of which will be elaborated on further on (Russel & Schneider, 2000).

2.6. BENEFICIARIES OF HOME BASED CARE SERVICES

According to the Department of Health (2001) and the Department of Social Development (2003), Home Based Care attempts to benefit and assist the following people:

- At risk or frail older persons
- At risk people with moderate to severe functional disabilities
- People recovering from illness, in need of assistance (e.g, post deliveries, post operation treatment and care)
- Terminally ill persons (e.g, cancer patients)
- Persons living with HIV/AIDS or other debilitating diseases/conditions (e.g, mental illness, substance abuse, cancer etc.)
- Any other disadvantaged or vulnerable group/person in need of support and care, especially children and women or people in crisis

Home Based Care programmes also aim to benefit the *caregivers* of these people, for example:

- Families and friends (e.g, of physically or mentally disabled, or terminally ill patients)
- Caregivers from the formal sector (e.g, professionals)
- Caregivers from the non-formal sector (e.g, NGOs, CBOs)
- Caregivers from the informal sector (e.g, community health workers, volunteers other community caregivers and church groups).

2.7. GENERAL PROBLEMS AND NEEDS AS IDENTIFIED AND PRESENTED BY THE BENEFICIARIES OF HOME BASED CARE

In the report “National Guideline on Home-Based Care and Community Based Care” issued by the Department of Health in 2001, several areas of need and intervention were identified based on a community assessment. The areas of need identified included: “*personal needs*” which incorporate physical/biological (medical) needs and psychological needs; “*environmental needs*” which incorporate factors such as physical environment, psychological environment and social environment; “*life style needs*” which include factors such as nutrition, exercise and rest, personal habits and sexuality, psycho-education, and recreation; and finally “*support needs*” which included establishing support groups for patients and caregivers, practical support such as household chores and shopping, social security support, spiritual support, counselling, and legal assistance (Department of Health, 2001, p. 30).

From the above identified needs, it is evident that a commonly occurring need of beneficiaries is the establishment and assurance of *psychological support* and emotional care. For example, *personal needs* include psychological factors such as stress, anxiety and depression; *environmental needs* include factors such as levels of adjustment to change, stressors in the environment and opportunities to relieve stress; *lifestyle needs* includes psycho-education for example in terms of reducing adverse behavioural habits; and *support needs* include factors such as patient self-support, group support and general counselling of peers, family, patients and caregivers (Department of Health, 2001; Gwyther & Marston, 2003; Knott, 2003). Thus it seems evident that focusing on the psychological and emotional needs as presented by the beneficiaries of Home Based Care is both highly necessary and relevant.

2.8. PSYCHOLOGICAL AND EMOTIONAL NEEDS OF THE BENEFICIARIES OF HOME BASED CARE

2.8.1. Terminally- Ill Patients

Persons affected by illness and disease are in general often psychologically distressed, emotional, anxious, and even depressed (Department of Social Development, 2003). Together with the fear of being diagnosed with a terminal illness, comes the fear of being isolated,

rejected and losing one's financial security, social status, and general independence (Shaw, 1992). According to Kelly, Raphael, Judd and Perdices (1998), life-threatening conditions may even be associated with complex clinical symptoms such as suicide, attempted suicide and suicidal ideation. Furthermore, emotional suffering may also result in outwardly expressed symptoms such as aggression, drug abuse, insomnia and a failure to thrive (WHO, 2002).

The psychological distress experienced in HIV/AIDS patients, specifically, is often much more complex and emotionally loaded than other diagnoses (Kaleeba, Kalibala, Kaseje & Ssebhanja, 1997; Shaw, 1992). For example, psychological support and disease acceptance has been reported to be worse for people with AIDS than for patients with other diagnoses (Baker & Seager, 1991, as cited in Kaleeba, Kalibala, Kaseje & Ssebhanja, 1997), and caregivers have similarly reported that providing care for AIDS patients is often more "time-consuming and stressful than caring for patients with other diagnoses" (Kalibala, 1995, as cited in Kaleeba, Kalibala, Kaseje & Ssebhanja, 1997, p. 15). Emotional strain associated with HIV/AIDS manifests itself as anxiety, loneliness, depression, shame and a wish to die (Mukisa, 1990, as cited in Kaleeba, Kalibala, Kaseje & Ssebhanja, 1997; Orsulic-Jeros, Shepherd, Britton, 2003). High levels of psychosocial distress including denial, blame of others for the infection, and hopelessness regarding the future are also often associated psychological symptoms (Kaleeba, Kalibala, Kaseje & Ssebhanja, 1997). Furthermore, individuals suffering from HIV/AIDS commonly suffer from poverty, stigma, discrimination and multiple losses, including the death of family members and friends. Such suffering may result in profound grief (WHO, 2002; Worden, 1993).

The need for HIV/AIDS patients to be loved, accepted and feel secure is amplified by the fact that many people with AIDS will have experienced rejection as a direct result of their diagnosis. Therefore, HIV/AIDS patients often experience a sense of multiple loss, which clearly exaggerates their psychological perception of the disease. Experienced losses may include: loss of control; loss of dignity; loss of future; loss of family support; and loss of body image and so forth. (Sims & Moss, 1991). Rejection, isolation and guilt may compound the feeling that the person is useless, hence their loss of self-esteem too (Sims & Moss, 2001).

2.8.2. Families and Significant Others

According to Shaw (1992) the experience of being diagnosed with a terminal illness, such as HIV/AIDS or cancer is catastrophic and traumatic for *both* the infected person *and* his/her family. Family members and significant others may experience emotional distress, anxiety, depression, hostility or mixed feelings, grief, loss and bereavement, and bereavement counselling may continue for several months after the patient's death (Shaw, 1992; DSD, 2003). Caring for a person in the terminal stages of an illness puts a great deal of pressure and strain on everyone concerned; families, children, friends and communities (WHO, 2002). The very nature of HIV/AIDS and its apparent call for a "continuum of care" in particular, serves to highlight these pressures and places an immense burden on the family system and family life-cycle in general (Davy & Ellis, 2000).

2.9. HOME BASED CARE COUNSELLING SERVICES: PSYCHOLOGICAL SUPPORT

2.9.1. Counselling Services: Emotional Care and Support

According to Russel and Schneider (2000), the counselling services provided within Home Based Care in South Africa vary considerably, with some models and or programmes offering extensive counselling services, and others offering very little. Nevertheless, counselling services, as well as emotional care and support, are regarded as being a necessary and integral part of the health care provision incorporated in to Home Based Care programmes, especially with regards to the dissemination of information on the illness/disease, and the provision of care and support for both the infected individual and affected family members and significant others. Counselling services and emotional support are seen as being able to alleviate some of the distress associated with a diagnosis of HIV, issues around bereavement and coping, as well as aiding prevention and behavioural change strategies (Russel & Schneider, 2000).

Tying in with these assertions and the evident need for psychosocial support, it is asserted that emotional care and support should be offered within a "continuum of care" framework, a term originally coined by the WHO (Van Praag, 1995). The "continuum of care" framework asserts that the range of needs of people living with HIV/AIDS should be addressed from

“diagnosis through to death and bereavement, as well as creating effective referral linkages between all actors in meeting these needs” (Russel & Schneider, 2000). In terms of providing emotional support within this framework, Home Based Care models are advised to offer counselling, and psycho-education on issues from acceptance of diagnosis, through to living with HIV/AIDS, and helping families cope (Sims & Moss, 1991). Bereavement counselling is also advised (Russel & Schneider, 2000).

Providing psychological support to family members of the terminally or chronically ill patient is very important within Home Based Care programmes as they usually provide a substantial amount of the care given to the terminally-ill person, and experience considerable emotional strain in the face of this task (WHO, 2002). Bereavement counselling is essential and should continue for as long as necessary. Addressing bereavement issues’ pertaining to any children involved is also advised, especially those who have been orphaned (WHO, 2002). Worden (1993) urges that health care workers and caregivers should encourage and facilitate family members and significant others to mourn the death of their loved ones. The four tasks of mourning as stipulated by Worden (1993) can be considered. They include “acceptance of the reality of loss, working through the pain of grief, adjusting to an environment in which the deceased is missing, and emotionally relocating the deceased and moving on with life” (Worden, 1993, p. 10).

Finally, according to Knott (2003), emotional care and support is especially important in the face of HIV/AIDS where there is no cure, and thus there is no alternative other than to focus on caring for the physical (medical) and psychological welfare of the HIV-infected individual, and his or her significant others.

2.9.2. Benefits of Counselling

HIV/AIDS has forced us all to accept a paradigm shift. This shift is from “curing to caring” (Knott, 2003, p. 51. As a result counselling and emotional support have come to be foreseen as an effective and appropriate means to allay the severe emotional stress coupled with terminal or chronic illness and disease such as HIV/AIDS (Shaw, 1992; Kaleeba, Kalibala, Kaseje & Ssebbanja, 1997). According to Kaleeba, Kalibala, Kaseje & Ssebbanja (1997), the

provision of psychological support and restoration of hope is associated with improved quality of life.

Psychological care and support for people with HIV/AIDS, in particular, plays a critical role in assisting people to better understand the need for prevention and to enable them to protect others (MacNeil, Mberesero & Kilonzo, 1999). Research indicates an integral connection between care and support and prevention strategies (Russel & Schneider, 2000). For example, an evaluation of the AIDS Support Organization (TASO) in Uganda revealed that providing counselling support facilitated family and community acceptance of people living with HIV/AIDS and affected behavioral change such as increased condom use. In addition 56.9% of patients made plans for the future and 51.3% wished to make wills, primarily as a result of receiving counselling (Kaleeba, Kalibala, Kaseje & Ssebbanja, 1997). Similar results were found by MacNeil, Mberesero & Kilonzo (1999) in a study conducted in Tanzania.

2.10. SERVICE PROVIDERS

2.10.1. Home-Based Caregivers as Service Providers

In order to ensure the proper management of Home Based Care programmes, different professional groups, both formal (e.g, doctors, nurses, psychologists) and informal (e.g, families, community health workers, faith-based organizations) are strongly encouraged to work together in collaboration as a multi-disciplinary team (Uys, 2003; Department of Health, 2002; 2001). In reality, however, it is evident that a majority of Home Based Care programmes rely heavily on the skills and services provided by caregivers for their success and stability, acting as the mainstay of Home Based Care programmes in most instances (Cameron, 2003). Caregivers therefore form an integral and important part of Home Based Care programmes, and without which many would be in non-existence (Department of Health, 2002).

Whilst some Home Based Care programmes are able to offer their caregivers a small remuneration for their services (Department of Health, 2002), generally speaking caregivers are expected to *volunteer* their services due largely to a lack of financial resources and heavy caseloads. According to research however, programmes with inadequate funding find it hard

to maintain volunteer commitment and hence the turnover of volunteer Home Based Care caregivers is often high (Department of Health, 2002).

2.10.2. Caregivers Defined- “Primary Caregivers” and “Home-Based Caregivers”

According to Uys (2003, p. 4) the care provided within Home Based Care settings may be provided by family or friend caregivers, which she refers to as Primary Caregivers. This care is then supplemented and supported by “trained” Home-Based Caregivers working in and for the community, usually on a volunteer basis (Department of Health, 2002; 2001). It is these caregivers that form the primary focus of this research project.

2.11. THE ROLE OF HOME-BASED CAREGIVERS

As defined by the Department of Health (2001) and Russel and Schneider (2000), the role of Home-Based Caregivers includes: preventative care; basic care (primary health care); rehabilitation; hygiene and safety; support and care to patient; counselling; running and administering support groups; bereavement counselling, health promotion; education and therapeutic education; emergency care; referrals; and household assistance.

Thus Home-Based Caregivers provide care and support services to patients, their families and communities on a variety of levels, starting at post-test counselling and diagnosis, through to bereavement and beyond (Department of Health, 2002). They also serve as a very important point of reference for referrals within communities and across multi-disciplinary teams of professionals and non-professionals (Cameron, 2003; Defilippi, 2003).

2.12. SUPPORT SERVICES PROVIDED TO HOME-BASED CAREGIVERS

2.12.1. Defining the Support Services Required

The Department of Health (2001) has proposed several standards of support services to be provided to Home-Based Caregivers. These include: supervision; safety protocols; appraisals; emergency plans; accessibility lines to information/communication; appointment of clinical consultants/ mentors; written disciplinary procedures; caregiver relief plan/ respite care; and caregiver support plan (e.g, social assistance, counselling services, and a bereavement plan).

2.12.2. The Urgent Need for Support

According to Russel and Schneider (2000), the management of caregivers needs to be closely addressed. Caregivers working within Home Based Care programmes continuously work with illness, disease, as well as death, and therefore constantly bear an incalculable burden (Rabow, Hauser & Adams, 2004). Feelings of sadness, guilt, anger, resentment, and a sense of inadequacy are commonly experienced feelings by home-based caregivers working in Home Based Care programmes (Rabow, Hauser & Adams, 2004). Furthermore, exhaustion, financial strain and continuous caregiving may all contribute to significant mental health morbidity, anxiety and even depression. As many as half of caregivers experience clinical depression (Rabow, Hauser & Adams, 2004). The emotional responses elicited in caregivers is both taxing and dramatic (Poss, 1981).

2.12.3. The Risk of Burnout and the Ongoing Need for Psychological Support

Caregivers working in Home Based Care and support programmes continuously run the risk of experiencing 'burnout' due to the very taxing nature of their job (WHO, 2002; Ross, Greenford & Bennett, 1999). Furthermore, according to the Department of Health (2002) and Ross, Greenford & Bennett (1999) burnout amongst caregivers providing care for HIV/AIDS currently contributes to a significant loss of personnel within Home Based Care programmes in South Africa, resulting in a huge strain being placed on both the formal and informal health sectors. It can, therefore, be seen to be somewhat mandatory that Home-Based Caregivers receive some level of ongoing psychological support in order to avoid cases of burnout.

2.12.4. Emotional and Psychological Support and Care

Emotional and psychological support and care for home-based caregivers may be provided in terms of supervision and debriefing sessions (Russel & Schneider, 2000; Department of Health, 2002). These may be conducted on an individual or group basis. Stress management classes, support sessions, mandatory leave and consultation with a psychologist from the formal health care sector, are all valuable and practical ways to alleviate some of the

emotional strain placed on home-based caregivers (Department of Health, 2002; WHO, 2002). Supervision provides home-based caregivers with a backbone to support and development, ultimately facilitating efficiency, learning and communication, and assisting in ensuring a higher standard for the quality of care (Davy & Ellis, 2000).

Finally, the importance of support services to home-based caregivers can be clearly discerned from research conducted by Ross, Greenford & Bennett (1999, p. 724), who indicates that it is “the stressors associated with caregiving which ultimately lead to caregivers dropping out”, and not the lack of “rewards”. Rewards (e.g, financial) do not necessarily appear to have a “protective effect”.

2.13. TRAINING RECEIVED BY HOME-BASED CAREGIVERS

2.13.1. Policy and Practice

According to the Department of Health (2001), all models of Home Based Care should have training and development policies in place for home-based caregivers. Cameron (2003) urges furthermore, that it is *essential* that home-based caregivers receive proper training to provide a high standard of care. If home-based caregivers are not equipped with the necessary and required knowledge and skills they need, they will not be able to function and cope as part of the multi-disciplinary health care team, and the Home Based Care programme will not succeed (Cameron, 2003).

Currently in South Africa, the “South African Qualifications Authority (SAQA) Act” (Act 58 of 1995) has created a new framework for education and training (Cameron, 2003, p. 33). However, presently there are no mechanisms in place for the “accreditation of home-based care workers or ancillary health workers” and the aim is to “develop national standards, recognized and registered by SAQA” so that home-based caregivers can access programmes and career paths and can gain accreditation and certification within the field of health care (Cameron, 2003, p. 33). This may prove to heighten the *motivation* for home-based caregivers to volunteer their services in the future, however, it may also prove to be a laborious and difficult process to achieve, especially given that the standardization of Home

Based Care programmes themselves, is in practice proving a difficult process as previously mentioned.

2.13.2. Training Requirements

Generally speaking, the training provided should include preventative, rehabilitation, and palliative care (Department of Health, 2001). Appropriate training material, equipment, supplies and personnel should be allocated, and the content of the training module/s determined by the needs, roles and responsibilities of the caregivers themselves. The modules should be flexible enough to allow for individual adjustment (Department of Health, 2002; 2001).

Furthermore, it is urged that training be holistic and circular, based on the Department of Health's curriculum for Home Based Care, which includes modules on the "role of community caregivers; basic information on Sexually Transmitted Diseases, HIV/AIDS, and Tuberculosis (TB); teaching and communication skills; spiritual and cultural issues; infection control; emotional care and support; social support; principles of palliative care and basic nursing care; nutrition; and care of the (family) caregiver/s" (primary caregivers) (Department of Health, 2002 p.15). Support and the sharing of knowledge and expertise between and within the formal and informal sectors should be apparent and circular in nature (Cameron, 2003).

Included in this holistic framework is the identification of psychological support for those who are terminally or chronically ill, their families, significant others and the community in which they live. Thus, basic counselling skills for psychotherapy may be beneficial to include in a training programme for home-based caregivers. Such skills may include verbal and nonverbal communication skills, basic listening skills, empathy and unconditional positive regard (Brems, 2001). Generally, the counselling skills required in terminal care are those required in all counselling work (Poss, 1981). However, the ability to tolerate close contact with dying and death also needs to be an internalized trait of home-based caregivers. Kübler-Ross (1970, as cited in Poss, 1981, p. 45) stresses that "unless the caregiver has come to terms with his/her own feelings concerning dying and death, s/he cannot become an effective caregiver to the terminally ill".

Therefore, caregivers should be aware that the fear of death, and death itself, can elicit profound emotional shock, and sometimes physical shock, for both the diagnosed individuals as well as for relatives, no matter how much it has been anticipated (O'Brien & Monroe, 1990). It is advisable that caregivers are knowledgeable about the five interrelated stages in the psychological process of dying and the grief process commonly expressed by family members once the patient has deceased (Kirschling, 1989). Training should also include knowledge of appropriate care and support for children experiencing bereavement, grief and or trauma.

Finally, caregivers need to acknowledge and understand when they need to make appropriate referrals to other health care sectors. They need to understand and be aware of their own limitations and boundaries. These issues can be discussed, defined and developed during training as well as during supervision.

2.14. THE FIVE MODELS OF HOME BASED CARE

2.14.1. General Overview

There is generally very little literature available pertaining to the models of Home Based Care. However, according to the Department of Health (2001; 2002) there are five models of Home Based Care which are currently in existence and can be identified. They include the 'Community- Driven Model', 'Formal Government Sector Model', 'NGO Home/Community-Based Model', 'Hospice Integrated Home-Based Care Model' and the 'Integrated Home Based Care Centre Model (Department of Health, 2001; 2002).

A common goal of each of these five models is to provide adequate care to patients and their families within the context of the home and the community, taking in to account socio-economic conditions, needs, constraints and resources (Department of Health, 2002). The survival and success of any model is largely dependent upon the availability of resources, the extent of community participation and the level of ongoing commitment and organizational capacity of the coordinating body (Department of Health, 2002). If the coordinating body is already well established in the community, with informed partnerships and referral

relationships established, there is often a stronger case for success and stability of the programme, as has been demonstrated in the research done on the 'Hospice Integrated Community Home-Based Care Model' (Department of Health, 2002).

2.14.2. The Five Models of Home Based Care

i) Community –Driven Model

The 'Community-Driven Model' as defined by the Department of Health (2002, p. 7) is primarily based on the premise of "integrated service provision through community and locally-driven initiatives". Unlike other models, where there is a central structure or coordinating organization, this model does not necessarily need to be attached to a community structure or organization (Department of Health, 2002; 2001). A community developer is designated responsibility for liaising with partner organizations and training volunteer caregivers, who then deal directly with patients and their families as necessary. Government departments or NGOs may also be approached for resources where and when required (Department of Health, 2002).

ii) Formal Government Sector Model

This model is led by governmental bodies such as health and welfare departments, and works in collaboration with various sectors (Department of Health, 2002). The home/community-based programme is organized at district level by multidisciplinary teams of doctors, nurses, social workers and so forth, within an institutional/ hospital setting. A patient is treated at the hospital and transported home by the hospital when possible. Home visits are undertaken by a professional nurse and community health worker/s. Patients can go to the clinic for follow-up treatment and can be referred back to the hospital when necessary. Other community organizations may assist the family and patient as needed (Department of Health, 2002, p. 8).

The advantage of this model is that the formal health and welfare services that coordinate and organize the programme are already well established and receive "financial and policy support from the government" (Department of Health, 2002, p. 8). This results in the model being highly organized and structured, and usually well established.

iii) NGO Home Based Care Model

This model is located within the community itself (Department of Health, 2002). The entire home-based care program is “initiated by a coordinating NGO (Department of Health, 2002, p. 2). Needs are identified and services provided by the coordinating NGO. The Home Based Care program may be financially supported by the coordinating NGO or another NGO, business or health sector, CBO or FBO. The home-based care team may include a professional nurse, social worker, project coordinator and caregivers/volunteers. All team members are based at the NGO site (Department of Health, 2002).

iv) Hospice Integrated Home-Based Care Model

This model is ultimately supported by ‘hospice’, and emphasizes a “continuum of care between all sectors of the health care system, as well as palliative care” (Department of Health, 2002, p. 11). It is similar to the NGO model but has the added benefit of being managed and supported by an already well-established NGO, namely ‘hospice’. A central concept of this Home Based Care program is ‘palliative care’. Palliative care is not foreseen as adequate or appropriate on its own when treating patients, but is regarded as an essential element in providing comprehensive care and support for terminally-ill people, for example, people living with HIV/AIDS (Department of Health, 2002).

v) Integrated Home/Community Based Care Centre Model (IHCBC)

This model is structured around a central care centre/ facility already established and located within the community, as in the ‘NGO Home/Based Care Model’ and the ‘Hospice Integrated Community and Home-Based Care Model’ (Department of Health, 2002). The centre is run primarily by volunteer caregivers, with the departments of health and welfare sending professional nurses and or social workers to provide services as is needed.

The centre determines and allocates services, ensuring that they are coordinated and managed effectively. Promotion of mutual support and collaboration between different components such as families, caregivers, clinics, hospitals etc. is much sought after and encouraged (Uys, 2003). Services provided may include: “pre-and-post test counselling for HIV/AIDS patients, HIV testing, training for family members and community caregivers/volunteers, distribution of IEC materials, facilitation of income-generating projects, supervision and monitoring of caregivers, conducting of home visits and patient follow-ups, referral to and from hospital

and other service providers” (Department of Health, 2002, p. 8). The centre may also act as a ‘halfway house’, providing day care to patients in need. The primary aim therefore is to integrate and link all service providers with patients and their families in a continuum of care (Uys, 2003).

2.14.3. Home Based Care Model Structures in Practice

Despite the Department of Health (2001) recently issuing national guidelines and programmes on how to implement, structure and organize Home Based Care programmes/models, it is nevertheless evident that in practice these Home Based Care models are often not as clear-cut or as structured as initially proposed or thought (Defilippi, 2003). This has primarily to do with the fact that Home Based Care programmes are relatively recent developments and a majority of them are currently in an infancy stage of development in South Africa (Department of Health, 2001; Russel & Schneider, 2000). Furthermore, most Home Based Care and support programmes developed in South Africa thus far have been developed and established through an unsystematic, needs-based effort (WHO, 2002). There is thus an evident lack of standardization amongst Home Based Care models, within and across provinces in South Africa, with Home Based Care developing in a fairly haphazard way, and being largely determined by available resources and existing affiliations or allegiances (Russel & Schneider, 2000, Defilippi, 2003). Identification of distinct Home Based Care models within organizations are often blurred and or integrated.

2.15. BENEFITS AND CHALLENGES FACING HOME BASED CARE

2.15.1. Benefits

The benefits of Home Based Care, for both affected households and health sectors, are numerous (DSD, 2003; Department of Health, 2002; 2001; Russel & Schneider, 2000). Several of these benefits include: a reduction in the incidence of hospitalizations, unnecessary referrals and the length of hospital stays; a reduction in the amount of stress placed on the primary health care system as a result of resources being redistributed and an increased awareness and education about minor illness, nutrition and general well-being, provision of increased support to various beneficiaries; a reduction in costs to families, for example,

hospital bills, transport costs, time spent away from work due to hospital visits; awareness and promotion of illness and disease is facilitated; increased possibility of drug compliance; provision of a holistic approach to care, for example psychological support, social support; care is more personalized, and the people living with HIV/AIDS feel less isolated from family and friends; and the promotion of job creation, especially within the informal sector (Department of Health, 2002; Uys, 2003).

Home Based Care therefore, ultimately provides a network of care organizations for those people who have ‘slipped through the cracks’ of formal health care systems (Department of Health, 2002). In light of the current HIV/AIDS epidemic in South Africa and noticeable increase in disease in general, the Home Based Care framework for intervention seems particularly relevant and necessary in a country so restricted and limited by resources.

2.15.2. Challenges

Home Based Care is a relatively recent development within South Africa, and a majority of practicing Home Based Care programmes are currently in a state of infancy. The implementation and practice of Home Based Care models and programmes are still very much experimental in nature and severely restricted by adequate funding and resources (Russel & Schneider, 2000). Furthermore, there is a valid concern regarding the ongoing sustainability of Home Based Care programmes with regards to prioritizing the use of volunteers as a cost-saving measure. When these volunteers are themselves impoverished and or even HIV positive, this poses both ethical and economic dilemmas (Uys, 2003). They too have human rights and should not be exploited and deemed to bare the burden of rescuing or resolving the current economic and resource shortages facing our country.

According to Russel and Schneider (2000), Cameron (2003), and (Uys) 2003, as well as in accordance with the objectives of this study, several genuine *challenges* pertaining to the *psychological and emotional support* both received from and provided by caregivers can be identified. These include caregivers experiencing: emotional and physical strain and stress; burnout; being restricted by the resources available, for example, being under-trained or untrained; receiving an inadequate support structure, for example debriefing or supervision; being challenged by emotions expressed by the beneficiaries of Home Based Care such as

rejection, anger, grieving and or bereavement on an ongoing daily basis; and the HIV/AIDS epidemic inevitably depleting the pool of caregivers themselves in the long run due to their own HIV positive diagnoses (Department of Health, 2001).

2.16. CONCLUSION

This chapter has reviewed some of the pertinent issues in this field of study, namely Home Based Care and HIV/AIDS. The nature and structure of Home Based Care has been explored, as well as the roles and functions of home-based caregivers working for such programmes. Particular attention was focused on the services (emotional and psychological) provided by and received by home-based caregivers.