CHAPTER 1

INTRODUCTION

1.1. INTRODUCTION

In the past decade there has been a significant increase in the overall burden of disease in South Africa (Department of Health, 2001). Communicable diseases such as tuberculosis, infectious diseases such as malaria, non-communicable diseases such as hypertension and diabetes, and various other health problems have all had, and continue to have, an impact on individuals, families and communities nationwide (Department of Health, 2001; World Health Organization (WHO), 2003).

The dramatic impact and effect that HIV (Human Immunodeficiency Virus) / AIDS (Acquired Immunodeficiency Syndrome) has had on individuals, their families, and communities as well as on health care services in general has been of particular concern. South Africa currently has one of the most rapidly growing HIV/AIDS epidemics in the world (Shisana & Simbayi, 2002; Russell & Schneider, 2000) and the impact that this is having on the health care system is highly problematic and alarming. For example, because the progression of HIV to AIDS can vary from anything from a few months to more than a decade, and because the advanced stages of HIV are chronic, with patients experiencing periods of relative health between relapses triggered by opportunistic infections, the need for health care has not only been intensified and increased but a need for a *continuum* of care has also developed (Department of Health, 2002). This has resulted in the quality of care provided by formal institutions and hospitals being strongly influenced and depleted (Russell & Schneider, 2000). Limited resources have forced formal health care services to ration services and resources, and in some occasions to be discriminatory in terms of who can and cannot receive health care. Thus, even if a hospital or other institutional care is deemed to be the required discourse for treatment, it may not necessarily be available. In addition, the burden and responsibility terminal/chronic illness and disease is increasingly being passed on to families and communities (Department of Health, 2001).

In order to address this general increase in disease in South Africa, and the evident shift of care being placed on the domain of the family and the community, it has become imperative that strategies within the public health sector be devised with the aim of utilizing the limited health care resources available, to the optimum, and making them accessible to a wider majority. According to the Department of Health (2002, 2001) and the Department of Social Development (2003) one of the best ways to achieve these objectives is through the implementation of Home Based Care and support programmes.

Home Based Care can essentially be seen as an alternative method for intervention to more westernized and institutionalized health care models. Care is ultimately brought in to the home environment, by both informal and formal caregivers, with the aim of utilizing resources to the optimum in a depleted environment. A continuum of care is therefore provided.

Numerous home-based care organizations are currently in existence worldwide, providing care and support for people living with terminal illness, mental illness and disability, as well as care and support for their families, and the communities they live in (WHO, 2003). Since the late 1980s systematic efforts have been made to implement and evaluate Home Based Care in Botswana, Zimbabwe, Zambia, Tanzania, Malawi and Uganda, which have primarily come in to effect in order to manage and cope with the HIV/AIDS epidemic in those countries (Russell & Schneider, 2000). In Uganda, for example, it has been found that the holistic approach adopted by Home Based Care has significantly improved the quality of care for people living with HIV/AIDS.

The need for Home Based Care is therefore not new, but the increase in disease, and in HIV/AIDS particularly, has intensified the need for such a response to be effectively devised and implemented within South Africa (Department of Health, 2002; 2001, WHO, 2002; Kaleeba, Kalibala, Kaseje & Ssebbanja, 1997). It needs to be developed as an alternative and ‘back up’ for people who require extended health care, but not necessarily hospital care, or patients that are discharged from hospital care early (Department of Health, 2001).

1.2. RATIONALE FOR THE STUDY

In the face of the HIV/AIDS epidemic in South Africa and the general increase in non-communicable diseases, the related complications thereof, and an ageing population's impending impact on communities, Home Based Care and support models have mushroomed. Everywhere there is a steep increase in the need for long-term care (WHO, 2002).

Yet despite this evident increase in need and implementation for Home Based Care models in South Africa, discussions and evaluations of Home Based Care programmes appear to be very patchy, and most often lacking (Russell & Schneider, 2000). This has primarily to do with the fact that Home Based Care is a relatively recent development, and a majority of practicing Home Based Care models are currently in a state of infancy (Department of helath, 2001; Russell & Schneider, 2000). Furthermore, most Home Based Care and support programmes developed in South Africa thus far, have been established through an unsystematic needs-based effort (WHO, 2002). There is, therefore, often a lack of standardization amongst Home Based Care models, within and across provinces in South Africa (Russell & Schneider, 2000). This ultimately affects the quality of services provided and received across the spectrum. Of major concern is the lack of evaluative data.

In response to these concerns the Department of Health (2001) issued a 'National Guideline on Home-Based Care and Based Care' in an attempt to offer some structure and guidelines for implementation. However the extent to which these guidelines have been implemented and adopted is currently largely unknown and ambiguous. Consequently the Cabinet of the South African government began annually allocating funds to the Department of Social Development for Home Based Care in 2000, with the aim of providing support and care for individuals suffering from terminal illness, especially those infected and affected by HIV/AIDS (Department of Health, 2001). In order to assess how best to utilize these funds the Department of Social Development (2003) requested an evaluation and analysis of the effectiveness on the five models of Home Based Care, suggested by the Department of Health (2001), in five provinces: Limpopo, KwaZulu-Natal, Eastern Cape, North West and Mpumalanga.

The five models of Home Based Care suggested by the Department of Health (2001, as cited in Department of Health, 2002) include:

- Community-Driven Model
- Formal Government Sector Model
- Non-Governmental Organization Home/Based Care Model
- Hospice Integrated Home-Based Care Model
- Integrated Home Based Care Centre Model

The 'Community-Driven Model' is primarily based on the premise of "integrated service provision through community and locally- driven initiatives" (Department of Health 2002, p. 7). The Formal Government Sector Model is led by governmental bodies such as health and welfare departments, and works in collaboration with various sectors (Department of Health, 2002). The NGO Home Based Care Model is located within the community itself and entire model is "initiated by a coordinating NGO (Department of Health, 2002, p. 2). The Hospice Integrated Home-Based Care 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). The Integrated Home Based Care Centre Model (IHCBC) 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 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.

To date, the only model which has been formally evaluated is the 'Hospice Integrated Home-Based Care Model' (Department of Health, 2002). In this study the 'Community-Driven Model' will be focused on. This model utilizes a variety of resources within the community, even utilizing and borrowing some of the skill and techniques from well established organizations such as hospice, and therefore provides quite an expansive exploratory ground for research.

The Tapologo HIV/AIDS programme in the North West Province has been chosen as the primary site for this investigation as little, if any, research has been conducted in this area

with regards to the provision of adequate care and support services. It was also chosen because it was an accessible and convenient research site for the researcher.

Working from the framework of this model then, this study will also endeavor to assess and evaluate the psychological support both offered *and* received by home-based caregivers working within this model of Home Based Care. Home-based caregivers form an integral part of Home Based Care programmes and without which many projects would evidently be in non-existence (Department of Health, 2002; Russell & Schneider, 2000). Their relationship with the community is vital to the success of Home Based Care and the quality of care provided by these programmes, and their role is central to the success and sustainability of Home Based Care and support (Russell & Schneider, 2000). Their role generally includes providing preventative care; basic care (primary health care); rehabilitation; hygiene and safety; support and care for patients; counselling; running and administering support groups; health promotion; psycho-education; emergency care; referral and household assistance (Department of Health, 2001; Russel & Schneider, 2000).

Appropriate and adequate psychological support is also an essential component of Home Based Care (Department of Health, 2002; WHO, 2002). According to the WHO (2002) the mental health of terminally ill and ill people, their family members and members of the Home Based Care team are all very important. Psychological support is foreseen as an effective and appropriate means of allaying the emotional stress often associated with terminal illness and disease such as HIV/AIDS (Kaleeba, Kalibala, Kaseje & Ssebbanja, 1997).

This evaluation can therefore essentially be seen to form part of a broader empirical evaluation of Home Based Care and support programmes, and endeavors ultimately to establish the level of psychological care and support, both offered *and* received by caregivers working within the 'Integrated Home Based Care Centre Model' at the Tapologo HIV/AIDS programme in the North West province.

1.3. RESEARCH QUESTIONS

The current study will attempt to provide answers to the following research questions:

- What are the general working conditions of home- based caregivers?
- What motivates community members to become home-based caregivers?
- What training in counselling and, or psychological care do home-based caregivers, working from the 'Community-Driven Model' of Home Based Care, receive?
- Who are the main beneficiaries, and what are their primary psychological needs?
- What kind of psychological care and support are caregivers able to offer and address on a day-to-day basis?
- What psychological support do caregivers receive themselves?

1.4. THE AIMS OF THE STUDY

The primary aim of this study is to determine the type of, and level of emotional and psychological support offered by home-based caregivers within Home Based Care programmes, and to explore the type of issues that home-based caregivers are dealing with on a day-to-day basis. A secondary aim of this study is to evaluate and determine the level of emotional and psychological support that is offered and received by home-based caregivers themselves, as well as the type of training that they receive.

1.5. LAYOUT OF THE REPORT FOR THE CURRENT INVESTIGATION

Chapter 2 will attempt to review the pertinent literature in this field of study. Chapter 3 will present the theoretical foundation for the study. In Chapter 4 the methodology employed in the collection of data and analysis is discussed, and Chapter 5 deals with the results and the discussion of the study, and finally in Chapter 6 a summary of the study is offered , as well as the conclusions, limitations and recommendations for the study and for future research.