

# **CHAPTER ONE**

## **CONTEXT AND PURPOSE OF THE STUDY**

### **INTRODUCTION**

For some time now community care and support have sprung up almost everywhere in the world, where the Acquired Immune Deficiency Syndrome (AIDS) epidemic have appeared, and have shown amazing creativity and compassion in providing comfort and hope to people living with, or affected by, Human Immunodeficiency Virus (HIV) (Uys, and Cameron, 2003). Community care can be described as the physical and emotional management of the patient, and the family members, who are either infected by the disease or affected by it. This is achieved largely within the informal structures of the community. This support strengthens the capacities of the patient and family to cope with the disease simultaneously creating an awareness of it and teaching skills on how to efficiently handle the disease.

The great majority of people with AIDS in low and middle-income countries are cared for at home (Akintola, 2004). Health services are beyond the reach of large sectors of the population, who are left to struggle to cope with the burden of the virus with minimal assistance from organizations. Not surprising therefore, volunteers in home based care have been called upon to assist in the caring for the sick. This has helped to alleviate the pressure on hospitals and, ultimately, the government's health services (Uys, 2001).

The high prevalence of HIV/AIDS in South Africa poses major challenges for both government and civil society, attempting to do their utmost to curb the spread of the disease and to help those infected and affected by it. Many responses to this challenge have consequently taken shape. One of the most noticeable developments is the emergence of home based care services. These developments have relied heavily on the use of volunteers who are trained and supervised to deliver basic nursing care and support to HIV/AIDS patients and their families.

Little is known about the factors that keep volunteers committed to these programmes, nor has sufficient research been undertaken in this field to highlight what their expectations from the organizations that they base themselves in, are. Because few surveys have been carried out, little is yet known about how many people are involved in home based care, what they do, what motivates them, and what contribution they make to society. Obtaining reliable information about volunteering and home based care is essential if this valuable resource is to be developed to its full potential.

The cost of training and developing home based carers is considerable and so there is a need to sustain their engagement in these programmes (Akintola, 2004). It is vital to know what motivates these home based carers to volunteer their time and services to the community in order that every effort is made to ensure their sustainability in the programmes. Despite the growing number of home based carers serving HIV/AIDS patients and their families, there is a paucity of literature on their motivations and expectations. If we know what inspires these home based carers to volunteer and how

their interest to serve may be sustained, home based care structures will be in a better position to adapt to these opportunities for learning and community empowerment, to accommodate the volunteers' expectations.

## **1.1 CONTEXT OF STUDY**

The study took place in eleven communities located in Wards Eleven to Seventeen – Inner and Outer West Municipal Wards. **(See Appendix One – the map of Mariannhill and the areas covered by COC).** These eleven communities are the areas serviced by the Community Outreach Centre (COC), St Mary's. Chapter Four describes the COC communities in greater detail. The communities are semi-rural, severely marginalized areas spanning approximately 35 kilometres west of the centre of Durban, the largest city in KwaZulu-Natal Province, South Africa. There are a total of 76 601 households in these Wards and a population of 244, 223 people (Urban Strategy, 2001). The inhabitants are predominantly Zulu-speaking people who have little access to education, skills development, employment and adequate health care facilities. The legacies of poverty, malnutrition, disease and violence predominate. The communities consist mainly of established, informal residential areas. The rating of the housing conditions has been assessed as formal housing in low service areas. Approximately 50% of houses have access to piped borne water in their homes, 45% use community stand pipes and about 5% are still dependent on river water. About 65% of households are connected to electricity. Approximately 75 to 80% of the population are unemployed. The Wards are characterised by high levels of alcohol and drug abuse, crime, domestic violence and

child and elderly abuse. There are more women than men, and women head most households.

The only district hospital between Durban and Pietermaritzburg, the St Mary's Catholic Mission Hospital, Mariannhill is a 200-bed Christian Missionary, State-aided district hospital. It is the referral hospital for 24 government community clinics and the only Catholic Mission Hospital in South Africa. The hospital, as is common with many hospitals all over the country, is currently inundated with HIV/AIDS patients. A recent survey conducted at St. Anne's Ante Natal Clinic, of the St. Mary's Hospital, revealed that 52% of women attending the clinic were infected with HIV/AIDS (COC Fact Book, 2005). With inadequate resources, funding and personnel, the hospital has had to rely on the community to assist them with the care of those living with HIV/AIDS and has developed the COC home based care programme. As the name suggests, the COC reaches out to the sick and ailing in the communities by training volunteers in home based care. The COC also ensures that the continuum of care paradigm is sustained in the patient's home.

## **1.2 MOTIVATION FOR THE RESEARCH**

Volunteers need to be appreciated, happy and content in their work environment to continue to volunteer time and service to the community. In order to keep them motivated and content, it is the responsibility of the organization to fully understand the factors that keep them motivated. The organization must ensure that their commitment to these

programmes is sustained. Volunteering as a home based carer in the health sector, within the current South African context, offers many challenges, as the home based carers are faced with on going death and dying as well as abject poverty and hopelessness. The research facilitator's observations (as manager of the programme) of the socioeconomic backgrounds of the home based carers of the COC, revealed the dire poverty these volunteers are faced with; and the daily contact with illness and death that they struggle with. However, this observation is yet to be tested by research.

Little recognition from community organizations and government, for the role home based carers play, is given. One would expect, therefore, that it becomes easy to lose the will and motivation to continue on this noble path. Very little has been documented on the motivations and expectations of home based carers. More importantly, there is a lack of literature that identifies and addresses ways of sustaining their levels of motivation, commitment and dedication. For the social sector to be able to sustain the services of a committed group of home based carers, they should look to finding the answers to the following questions:

- What meanings do home based carers attribute to the terms 'volunteer' and 'home based carer'?
- What factors motivate home based carers to volunteer?
- What do home based carers expect from the organizations that utilize their services?

- What do home based carers perceive the role of NGOs, CBOs, and FBOs to be in sustaining their commitment to volunteer?

Whilst the research facilitator, in her capacity as the manager of the home based care programme of the COC, formulated her own answers to these questions, she felt that they should be empirically validated to satisfy the interest shown by local and international visitors and funders. Traditionally research has relied upon a ‘top-down’ approach. The research facilitator saw the need to involve the home based carers themselves in a participatory process to research this topic and engage them in a process on how to improve the existing programmes offered by the COC. This will be discussed later in Chapter Five, research methodology.

This study would benefit the Community Outreach Centre, St Mary’s, as the Centre has not canvassed the motivations and expectations of its home based carers before. To date the COC is unsure of what attracted these home based carers to volunteer or remain as volunteers for an extended period of time. It was hoped that this study would influence the COC’s response to current, and prospective home based carers and be of benefit to other organizations utilising the services of home based carers, as discussed earlier.

### **1.3 CRITICAL QUESTIONS**

Research always commences with one or more questions or hypothesis. Questions are asked about the real nature of a situation, while hypotheses are statements about how

things can be. A good research question can be answered by collected data and the answer thereof cannot be foreseen prior to the collection of the data (De Vos, 1998).

The critical research questions in this study were:

- What are the home based carers' understanding of the terms 'volunteer' and 'home based carer'?
- What motivates home based carers to join the COC programme?
- What expectations do the home based carers have specifically of the COC and the role it should play in sustaining their commitment in the programme?
- What do the COC home based carers believe the role of other NGOs, CBOs and FBOs should be in sustaining the commitment of home based carers in the Mariannhill community?

#### **1.4 RESEARCH METHODOLOGY**

This study used a qualitative research approach and was field focused. It was exploratory in nature. This type of research is usually carried out when the researcher wants to explore areas about which s/he has little or no knowledge.

The purpose of exploratory research is to gain insight into a situation, phenomenon, community or person. The need for such a study usually arises out of a lack of basic information on a new area of interest (Bless and Higson-Smith, 1995). Babbie and

Mouton (2001) concur that this approach is typical when a researcher examines a new interest or when the subject of study itself is relatively new. As indicated, we know very little about home based carers' motivations, their understanding of their role as volunteers and their expectations.

This study was guided by the following two theories: person-centered approach and participatory learning. The person-centered approach postulates that individuals have within themselves vast resources for self-understanding and for altering their self-concepts, basic attitudes, and self-directed behavior. These resources can be tapped if a definable climate of facilitative psychological attitudes can be provided (Rogers 1951). Participatory learning is a people centered way of engaging and mobilizing the community thus providing the research facilitator with crucial pointers on how to combine a clinical and developmental paradigm.

The study took place in two phases: a pilot project, and a participatory action research component that used focus group discussions. The pilot study was conducted with twenty five home based carers who voluntarily chose to join the study. The purpose of the pilot study was to perceive and interpret the home based carers' definition of home based care, to explore their motivations, expectations and experiences as home based carers, and to make sense of their experiences in the COC programme. It was hoped that this pilot project would help to alert the research facilitator to relevant themes in this field and formed Phase One of the research. The main limitation of this phase of the study was researcher bias as the research facilitator was the manager of the COC, and may have



inadvertently attempted to portray the COC in a positive light. The other limitation was the top-down, 'elitist ownership' approach and as such meanings could have been lost in the study, especially as Zulu was not the main language of the research facilitator but was the main language of the participants.

As the research facilitator's primary intention was to explore the motivations and expectations of a locally specific group of home based carers caring for HIV/AIDS patients, it was felt that a participatory process, engaging a group of home based carers as co-researchers, would render a more reliable outcome. The participatory research strategy was chosen in keeping with the theoretical approaches of person-centered and participatory learning that were used through out the study. This formed Phase Two of the study.

Five home based carers were elected by the home based carers as co-research facilitators. They were trained to assist the research facilitator in this participatory study. Using stratified random sampling, the focus groups were selected according to the different category of trainings the home based carers received at the COC namely Group One (General Training in HBC), Group Two (Palliative Care training), Group Three (Child Care Training), Group Four (Community Facilitators), and Group Five (home based carers who are currently in employment). **(See Appendix Two for the Training Curriculum of COC)**. Five Focus Groups were selected. Each focus group was selected using systematic sampling. Six home based carers per focus group were selected. In total,

five focus groups were identified with six home based carers per group providing a total sample of 30 home based carers. Two group meetings were held with each focus group, each lasting an hour and a half long.

The information gathered was analyzed and reviewed for patterns and themes. The findings were recorded and recommendations were made to the COC and other organizations utilizing home based carers in their programmes and are summarized in Chapter Seven, recommendations and conclusion. A further method of data collection used was semi structured interviews with key informants, who were managers and staff of other home based care programmes utilizing volunteers, in both phase one and two of the study.

## **1.5 ASSUMPTIONS OF THE STUDY**

The study had several underlying assumptions. These were:

- To develop a locally specific view of home based care from an individual and group perspective of home based carers as their perceptions would be more meaningful than those provided by texts and service providers.
- By engaging home based carers to qualify their motivations and expectations as home based carers they would become instrumental in developing a more comprehensive training programme and incentive structure that would help to sustain the project.

- By engaging home based carers they would be further empowered.
- By making the study more culturally sensitive and appropriate for the socio-economic and political context within which the home based carers operate, the findings would refine the concept of home based care, thus making it more locally specific.

## **1.6 LIMITATIONS OF THE RESEARCH**

This research was a qualitative research with an exploratory purpose. The research facilitator was more concerned about trying to elucidate the innermost experiences and perceptions of home based carers involved in the COC programme rather than trying to generalize the findings. The sampling method and the small sample size used suggest that the results of the study may not be applicable to all home based carers. That was acceptable because it was intended to be a locally specific study of home based carers in the Mariannhill area.

Every effort was made to ensure that home based carers' meanings were not lost in translation but we cannot rule out that some inaccuracies may have crept in. It is hoped that the regular meetings and discussions with the co-researchers, who were Zulu speaking, would have kept this to a minimum. As the manager of the COC, it is hoped that the research facilitator's personal interest in the study would not have resulted in researcher bias. The engagement of co-researchers in this research; the frequent research team meetings; and the field observations, should have kept such a bias neutral.

## 1.7 ETHICAL CONSIDERATIONS

Ethical issues abound when research is conducted on participant's personal life situations and especially when the research study is conducted with HIV/AIDS as the backdrop (Akintola, 2004). According to Miles and Huberman (1994), the ethical considerations of research fall into three categories: the research project/study itself, the researchers, and the participants. Some ethical questions in these categories include:

- ***The research project/study:*** Is it worth doing? Was it conducted with integrity and quality? What are the benefits? Who owns the study?
- ***The participants:*** Did they give consent? Was their privacy and confidentiality respected and maintained? Were they harmed in any way?
- ***The researchers:*** Did they have competence in the area of study? Were they honest and truthful in their interactions with the participants and in recording and reporting the findings?

The following steps were therefore, taken to safeguard the rights of all involved in this study:

- Permission was sought from the Executive Committee of the COC; St Mary's to conduct this study. **(See Appendix Three for consent form.)**
- A full explanation on the purpose of the study was given to all home based carers of the COC and verbal consent was obtained of the sample population. Whilst this study did not aim to, in any way, establish or hint at a home based carer's, or his/her family member's HIV status, the two issues of informed consent and confidentiality were exhaustively discussed to ensure that participants knew the intent of the study before committing to the process. All participants were given

the option of joining the focus groups or opting out. The sampling process was carefully discussed to ensure that the sample would not be perceived as favoured if one was not selected.

- Information on the rights to refuse consent and withdraw from the study, without negative sanction, was given.
- Data gathering was limited to eliciting information that was relevant for the study.
- Participants' anonymity and privacy were maintained by keeping all information obtained, confidential. Where direct quotes were cited, the participants were not identified by name. Confidentiality is also an important ethical issue when dealing with people who talk about their personal experiences and feelings in case studies. At the outset of all focus group discussions, ground rules were set by the home based carers themselves. Confidentiality was paramount for all focus groups. The research team concealed all names and addresses of the home based carers to guarantee anonymity. Each focus group session ended with debriefing, especially after emotionally challenging issues and experiences were shared. This was to ensure that ethical obligations were carried out and that the emotional needs of the home based carers were taken care of by referral to appropriate quarters.
- Findings were honestly and accurately recorded.
- The recommendations from the findings were made available for the purposes of enlightening the COC and other such organizations about the importance of acknowledging and understanding the motivations and expectations of the home based carers in their programmes.
- The final report will be distributed to all participants, co-researchers and the COC.

## **1.8 PRESENTATION OF CONTENTS**

### **Chapter one – Context and Purpose of Study**

This chapter discusses the background to the study, the statement of the research problem, significance of the study, as well as the key research questions addressed in the study. It also presents a layout of the chapters in the thesis.

### **Chapter two – Volunteerism: A Literature Review**

This chapter presents a review of the relevant literature on the role of volunteers in general. The review begins by examining the definition of a volunteer. It explores the importance of researching volunteering and highlights criteria consistent with volunteering. It further considers the motivations of a volunteer; the burdens of volunteers; how they fit in the structures of Non Governmental Organizations (NGOs); and the role they play in the health sector. The chapter concludes with a discussion on the key aspects in managing volunteers.

### **Chapter three – Home Based Care: A Literature Review**

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 presented 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 home based care has to play in the fight against HIV/AIDS.

#### **Chapter four – Nature of Work of the COC**

This chapter discusses the history and mission of the COC; the core components of this programme; and the role of the home based carers in the sustainability of this programme.

#### **Chapter five – Research Methodology**

This chapter outlines the methodologies used during the study and focuses on the research design, sampling strategies, and the data collection tools. It also elucidates on the ethical considerations and discusses the validity and reliability of the study.

#### **Chapter six – Analysis and Discussion of Results**

This chapter considers the data analysis process and discussions are centered on themes and sub-themes that emerged from the study. In order to fully appreciate the scope of care provided and the impact it has on the home based carers' lives, case studies were used to 'give voice' to the experiences of the home based carers who participated in the study.

#### **Chapter seven – Conclusion and Recommendations**

This chapter presents an overview of the thesis together with the conclusions and recommendations. The chapter concludes with suggestions for future research.