

# **CHAPTER SEVEN**

## **RECOMMENDATIONS AND CONCLUSIONS**

### **INTRODUCTION**

This chapter reintroduces the research study's rationale and the central issues that stimulated the research process. A broad overview of the main findings will be presented and linked to the study's theoretical framework. Finally, the principal recommendations will be discussed and areas for future research are outlined.

### **7.1 RATIONALE AND CONTEXT**

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 that utilizes their services to fully understand the factors that keep them motivated. One must ensure that their volunteers' commitments to these programmes are sustained. Volunteering as a home based carer in the health sector, within the South African current context, offers many challenges, as the home based carers are faced with on going death and dying as well as abject poverty and hopelessness.

Little recognition for the role home based carers play is given. One would expect that it would become easy for home based carers 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 exploring and describing 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 (NGOs, CBOs and FBOs)?
- What do home based carers perceive the role of NGOs, CBOs, and FBOs to be in sustaining their commitment to volunteer?

Over a period of time a number of home based carers have been involved in the care and support of HIV/AIDS patients under the auspices of the Community Outreach Centre (COC), St Mary’s, in the Mariannhill region. However, not much was known about their motivations and expectations as home based carers and neither had the COC canvassed this information before. Whilst the research facilitator, in her capacity as the manager of the home based care programme of the COC, developed her own assumptions regarding the answers to these questions, she felt that they should be empirically validated to enable the COC to further sustain the inherent commitment of home based carers in the programme.

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. The findings would also influence the COC's response to current, and prospective home based carers. Significant emphasis was on the participants and their world views. Participatory action research has an explicit commitment to the empowerment of participants, providing them with an opportunity to shape the structures that coordinate their home based care voluntary services. It was hoped that the findings of this study would be of benefit to researchers and local organizations that rely on home based carers.

## **7.2 THEORETICAL FRAMEWORK**

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 clinical and developmental paradigms.

### **7.3 RESEARCH APPROACH**

This study used a qualitative research approach and was field focused. It was exploratory in nature. This type of research was appropriate because the research facilitator wanted to explore areas about which there was little, or no, locally specific documented information.

A pilot study was conducted using a non-probability selection principle. Twenty-five home based carers 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. This formed Phase One of the research. The research facilitator was preoccupied with the home based carers' world views.

A 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 to conduct a participatory study. Using stratified random sampling five focus groups were selected. Six home based carers per focus group were selected using a systemic sampling technique. In total, therefore, five focus groups were identified with six home based carers in each group. 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**). Two group meetings were held with each focus group, each lasted an hour and a half long.

Information from focus group discussions, were gathered and recorded on newsprint. 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. The co-researchers took field notes and observed participants in group settings. The research team met to analyze the information gathered and review patterns and themes that were emerging. The data analyzed was viewed as a collaborative effort between the research facilitator and the co-researchers. The participants' involvement in a participatory action research approach of home based care enhanced the validity of the study and ownership of findings. 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 Six.

## **7.4 OBJECTIVES AND MAIN FINDINGS**

### **7.4.1 Objectives**

In order to gain an understanding of the motivations and expectations of home based carer in the COC programme; the study had the following five objectives:

- To understand the home based carers' definition of the terms *volunteers* and *home based carers*.
- To identify the factors that motivated the home based carers to volunteer
- To define their expectations as home based carers
- To engage them in a process of developing suggestions on how to improve on the existing programme.
- To explore what home based carers believed the role of other NGOs, CBOs and FBOs should be in sustaining their commitment to serving the Mariannhill community.

#### **7.4.2 Main Findings**

The participants' were predominantly female; between the ages of twenty and thirty years (50%). Seven percent were males. 80% of participants were single. All were Black and had Christianity as their religious base. All participants had had some personal experience with handling death, bereavement and illness. For 80% of the participants, volunteering at the COC was their first volunteer experience in a home based care organization.

Chapter Six discussed the data collected to investigate these objectives. A synopsis of the major findings is discussed in this chapter and is outlined below.

- Participants' defined a *volunteer* as: someone who provides a service of his/her own free will, without the expectation of being remunerated. Participants defined

a *home based carer* as: a volunteer who is trained in home based care to care of the sick in their home. This person is well respected in the community, values confidentiality and sees himself/herself as God's helper. The definition of *volunteer* and *home base carer*, as suggested by the participants, was in keeping with the commonly used definition of the terms as outlined in the literature studies in Chapters Two and Three. The suggested definitions allude to the factors that may motivate the participants to volunteer as home based carers and it also hints at their expectations as volunteers. The suggested definitions also set the tone for understanding the motivations and expectations of the home based carers of this study.

- Participants described the following as their main intrinsic motivational factors for volunteering at the COC: altruism – selfless service to the community which is a philanthropic and humanitarian gesture; bringing comfort and hope to ill patients and their families after having had personal experience with illness and death; the spirit of Ubuntu which is characterized by sharing, care and support; religious reasons leaning strongly towards the ‘Golden Rule’ which is to do for others as you would like them to do for you; repayment of ‘debt’ to the community for the care and support they had received when they were in crisis; empowerment through capacity building and skills acquisition; and employment opportunities. Home based carers are generally females. Clearly, from their own family experiences they knew how difficult and important it was to take care of people living with HIV/AIDS. Through their personal experiences, they had not

only learnt about the disease itself, but had also experienced the psychosocial dynamics of dealing with HIV/AIDS patients. Having themselves experienced feelings of denial, anger, despair and frustration; home based carers had more than just their training manuals to offer to the patients and their families. Their firsthand knowledge translated into empathy and compassion when caring for their patients and their families (Edoh, 2004). But for all the participants of this study, it was their religious faith and indebtedness to the community, that enabled them to channel the empathy and compassion they felt into care giving. A strong sense of 'oneness' with the community and Ubuntu strengthened them for the considerable challenges and sacrifices that lay ahead in their chosen roles as home based carers.

- Participants emphasised the following needs and expectations as home based carers of the COC: a need for ongoing training opportunities; and expectation of personal development, personal contact with the organization and patients, and acknowledgement and appreciation for the service they provide. Despite the many challenges that they faced, the training they acquired through formal and practical means empowered them on a personal level. In a context where most people have little or no formal education, the training in home based care provided them with a certain standing and recognition in their communities. Once identified as resource people and sources of help, the home based carers' expectations of personal contact with patients and the wider community, and



recipients of appreciation and recognition for their service, gave them a sense of fulfillment and self worth.

- Participants perceived the role of NGOs, CBOs, FBOs in sustaining their commitment to be as follows: holding government accountable for promises made, especially with regard to health care; actively addressing the poverty issue by developing innovative poverty alleviation strategies; acting as agents of change to improve the quality of peoples' lives. The home based carers viewed NGOs, CBOs and FBOs as well placed agents of social change to promote the involvement of home based carers as information conduits to ensure that any reconstruction and reunification initiatives at a community level are brought to the attention of the government and/or decision makers. In so doing the challenges and expectations of home based carers could be voiced and their input may be used to shape the government's care response to the HIV/AIDS pandemic. The home based carers felt that NGOs, CBOs and FBOs should hold the government and other key decision makers accountable for promises made and answerable for unmet promises. Home based carers felt that by working closely with government and other stakeholders, NGOs, CBOs and FBOs could lobby for the rights and recognition of home based carers, patients and communities. Clearly, these organizations should be more critical of the role they play in: assisting volunteers and home based carers to organize themselves into a formal body and campaign for their rights and quality service; challenging government with regard to backlogs in service delivery; and facilitating the emergence of interagency alliances to ensure a collaborative response to the HIV/AIDS pandemic.

While the small number of cases and low degree of control affected overall generalisability, the themes that emerged do have significance for organizations utilizing home based carers.

## **7.5 RECOMMENDATIONS**

A number of key recommendations arose out of this study. While home based carers' motivations and expectations may differ from region to region, it is important for organizations utilizing home based carers to understand what their motivations and expectations to volunteer, are. The following recommendations emerged from the study, and will be discussed as follows: practical recommendations, research recommendations, and policy recommendations:

### **7.5.1 Practical recommendations:**

- Home based carers value personal contact with the members of the organization they serve. To sustain a dedicated and long serving volunteer force, it is imperative for the 'employing' organization to engage the home based carers in dialogue – they must be kept abreast of the direction in which the organization is heading; the role they will be playing (and will be expected to play), in accomplishing the organization's goals; and they wanted to be rewarded and recognized for their contributions to effective service delivery.
- Support groups for home based carers need to be established and debriefing and counseling services should be made available to them, should they require it.

- Similar such exercises should be conducted with home based carers at regular intervals as this would give the organization an indication of how effectively it is treating the home based carers, and more importantly, what it should do to keep the home based carers attracted to stay on in the noble cause of volunteering

#### **7.5.2 Research recommendations:**

- More home based care organizations should carry out similar investigations to establish what their home based carers' motivations, needs, and expectations are. This will increase organizations' retention of home based carers in their programmes as it affords them opportunities to address the gaps between the expectations of home based carers and the opportunities they are afforded.
- More research needs to be undertaken to establish how the burden of care weighs on the home based carer, and by extension, onto his/her family.
- Research needs to also be undertaken to investigate how the emergence of home based care has affected the health care institutions, with special focus on the frequency of in-patient re-admittance into hospital, after initially being discharged into the care of home based care organizations.

#### **7.5.3 Policy recommendations:**

- Home based carers have motivations that spur them on to volunteer their services in care focused organizations. The challenge for organizations is to pin

point what these motivations are and to, accordingly, develop policies on home based care. They need to be engaged in active dialogue with key public officials such as project managers and staff of existing home based care programmes, local/provincial/national government officials, health personnel, and educational institutions with a view to shaping these policies.

- Engage home based carers in focus group discussions; allowing them to brainstorm possible ways for organizations to actualize their expectations; and empowering them to become active agents of personal and social change - were found to be useful methods for the employing organization to identify what home based carers' expectations were and what areas needed to be addressed. Armed with this first hand information, organizations can make representation at government levels when policy formulation, on volunteers, takes place.
- Every effort must be made to engage NGOs, CBOs, FBOs and home based carers in dialogue and active partnership as lobbyists, activists and agents of social change if effective and relevant policies are to be developed and accepted.
- All volunteers should be enrolled into one volunteer body, ensuring that they are given a voice. This registered entity could then champion the cause of volunteers in a formal manner.

## **7.6 DIRECTIONS FOR FUTURE RESEARCH**

The findings of the study discussed in Chapter Six, and this chapter, confirm that home based care is a practice built on community relationships. The pivotal role the home based carers play cannot be overemphasized. It therefore becomes critical to determine what the motivating factors and expectations of home based cares are, in care and service delivery to HIV/AIDS infected and affected people. Further research is indicated. Some of the possible future research questions are:

- Is a model of home based care of people who volunteer ‘for altruistic reasons’ or ‘out of the goodness of their hearts’ sustainable? If not, what are the alternatives?
- How do organizations who utilize home based carers currently respond to the motivations and expectations of their home based carers? How could the needs of home based carers be further addressed?
- What can be done to raise awareness within communities, about the nature, structure and purpose of volunteering in home based care programmes to increase the number of volunteers in that home based care programme?
- Because of the emotive nature of the work of home based carers, further research is required into the well- being of home based carers and how burnout can be prevented. The findings will also be useful for designing appropriate interventions and support structures for home based carers.

- What are the motivations and expectations of paid home based carers? Are they different from those of the unpaid home based carers?
- What role does religion play in mitigating the burden of care on home based carers? Should organizations utilizing home based carers be sensitive to, and tolerant of, home based carers' religious affiliations?
- What policies need to be developed to sustain the valuable services performed by home based carers?

## **SUMMARY**

This study brings to the fore the need for organizations utilizing home based carers to establish and understand their motivations and expectations to volunteer as home based carers, and to proactively address these issues, if this invaluable resource is to be retained. Although many home based carers 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 and seek to end the misery of community members. In the process they often confront other problems that complicate their own lives and that of their families. Home based carers play a major role in mitigating the burden of care for chronically ill and HIV/AIDS patients and they constitute the backbone of the model of home based care rendered by

the COC. They are thus an invaluable resource to affected households, communities as well as the health care system (Akintola, 2005).

While acknowledging that this study is localized to the home based cares of the COC in exploring their motivations and expectations as volunteers, it fails to provide information on the magnitude of problems encountered by home based carers. In his research, Akintola (2005), quoted case studies that highlighted the daily painful realities of the lives and work of home based carers, and, by extension, the challenges of the home-based care organizations that made use of volunteers. This was found to be quite the contrary in this study as one was clearly in awe of the fact that, despite the painful realities of their lives and trials and tribulations, the home based carers appeared positive and enthusiastic about serving their communities. A sense of Ubuntu prevailed. They appeared to use this opportunity to resolve some of their own unresolved issues of bereavement and loss of loved ones.

It is suggested that the assessment of the motivations and expectations of home based carers in the country be ongoing, in order to better understand what factors attract and retain volunteers in home based care organizations. This will be useful in the development of national policies on home based care in the country and hopefully lay the foundation for an effective, sustainable and scaled-up home based care model.