

CHAPTER FOUR

NATURE OF WORK OF THE COMMUNITY OUTREACH CENTRE (COC), ST MARYS

INTRODUCTION

As discussed in Chapter One, the study was undertaken in eleven communities located within seven municipal wards (Eleven to Seventeen), in the Mariannhill region. The participants of the study were home based carers, who had volunteered at the COC programme. This chapter discusses the history and mission of the COC; the core functions of this programme; and the role of the home based carers in the sustainability of this programme. As home based care is an integral component of the COC, efforts must be made to understand the motivating factors and expectations of the home based carers engaged in service delivery. This will help shape the COC's responses to the home based carers, and will assist the COC to improve and build on its current handling of home based carers.

4.1 THE HISTORY OF THE COC

According to official COC sources (COC Handbook, 2005), the COC was established in 1997 when nurses working in St Mary's Hospital noticed that malnourished children who were treated at the hospital, often returned. One of the nurses, Sr Ntombifuthi Mthalane, suspected this might be due to the fact that the patients lacked knowledge of how to prepare nourishing food and a balanced diet. She then decided to start a vegetable garden on the hospital's premises. Mothers from these communities

were brought in and taught gardening. They learnt how to plant vegetables that could be cooked to provide nutritious meals at low cost. This service proved invaluable for HIV/AIDS patients treated at the hospital. However, shortly after being discharged many patients were being readmitted because the care at home was inadequate or sometimes non-existent. The concept of reaching out to patients in their own homes, with a view to offering basic nursing care, was consequently conceived.

In 2004 the Community Outreach Centre transformed into an independent Non-Governmental Organisation. It had its own Board of Management and Executive Committee. The new entity works in very close partnership and liaison with the Hospital. It has a staff composition of seventeen – thirteen of whom have been employed from the COC's pool of home based carers. **(See Appendix Five for the COC Organogram).** There are two distinct advantages of obtaining an independent status as an NGO: the COC has more scope and freedom to shape its work; and the freedom to network at different levels augurs well for enhanced service delivery. The new entity has the ability to focus on home based care, as well as on developing an increasing number of programs for children orphaned and made vulnerable by HIV/AIDS.

The COC currently has 352 active volunteer home based carers who care for, on average, 900 adult patients and 1500 orphans per month, in the immediate vicinity of the St Mary's Hospital, Mariannhill (COC Fact Book, 2005). 40% of these home based carers have been in the programme for five years and longer (COC Fact Book, 2005). The longest serving home based carer has been in the COC programme for

eight years and the shortest serving home based carer for eight months (COC Fact Book, 2005). The research facilitator is the manager of the COC.

4.2 THE MISSION STATEMENT OF THE COC

The overall aim of the Community Outreach Centre is to improve the holistic health and quality of life of people through education. The Centre offers a number of projects that address some of the major problems that face people in local communities, namely: malnutrition, poverty and HIV/AIDS. It believes that through the empowerment of local communities they will be enabled to face and address the challenges and problems of the HIV/AIDS pandemic by developing innovative and community –based approaches.

4.3 FUNDING

The COC has been fortunate to access funding from both national and international funders, mostly in three-year cycles. Below is an outline of the previous and current funders.

4.3.1 Previous Funding

Components of the COC programme were funded by: Nkosisiphe, Masibambisane, and Masisizane HIV/AIDS Community Support Projects.

4.3.2 Current Funding

COC's current funding is largely outsourced through international funding organizations. CARITAS Germany, a confederation of 162 Catholic relief, development and social service organizations working to build a better world, especially for the poor and oppressed, in over 200 countries and territories; and Catholic Relief Services, a Christian based consortium, are two of COC's main funders. COC also has a locally based funder: National Brands.

4.4 A DESCRIPTION OF THE COMMUNITIES SERVED BY THE COC

The COC is situated in the Mariannhill Mission Station, 30 kilometres west of Durban on the highway between Durban and Pietermaritzburg. COC, although a separate entity, is situated on the premises of St. Mary's Hospital Mariannhill.

These communities emerged as largely informal settlements, with sub economic housing, to accommodate those affected by the forced removals, as promulgated in the Group Areas Act, Act No 41 of 1950. It borders on an industrial area, providing accommodation to labourers and commuters. However, the demand for accommodation has exceeded the infrastructure to serve these areas resulting in poverty, malnutrition, disease, overcrowding, and violence (COC Fact Book, 2005).

The communities around the Mariannhill hospital consist mostly of established informal residential areas. In most communities the rating of the housing conditions have been assessed as formal housing, low service areas. While the infrastructure has been partly developed during the past years especially in the more rural communities,

the Census 2001/Ward profile 2003 reveals that the conditions of the formerly better-developed areas seem to worsen with an increase in informal houses and shacks. This partly resulted from an increase in the population of an approximate average of 30% between 1996 and 2001 in all communities (Census 2001). While more and more families and individuals settle around the Mariannhill area in the hope of finding employment, the figures referring to labour force depict a minus of approximately 28% in the total labour force between 1996 and 2001 (Census, 2001). As an example, a survey conducted in Luganda (Ward Eleven), one of the communities serviced by the COC, only nine percent of the persons living in the area were employed (3700 out of 39000). 79% of the households reported to have no monthly income, while 30% of the households reported to have no annual income at all (Census 2001).

While access to water, sanitation and electricity has improved during the last few years, increase in poverty and unemployment remains the major concerns in the areas served by the COC (COC Fact Book, 2005).

4.5 CORE FUNCTIONS OF THE COC

There are three core functions of the COC. The first is the home based care component of the project. Home based carers, under the COC, are volunteers. They do not receive any form of monetary remuneration. They are selected by local Ward Councillors, Health Fora, and Church Parishes. They are highly regarded in their communities as trusted and responsible members. They receive training in basic home-based care, enabling them to offer basic care to the sick and to educate primary caregivers of the sick, on health issues, and how to care for their relatives in their

homes. Home based carers are neither nurses nor community health workers. They complete minimum training before being allowed to offer services to patients, on their own.

The second core function of the COC is to work with Orphan and Vulnerable Children (OVC). This is a three pronged programme that: facilitates psychosocial support groups in the schools; conducts home visits to the OVC to ensure that their basic needs are being met; and runs two 'drop-in centres'. A 'drop-in centre' can be described as a response by the community to accommodate and care for the increasing number of orphans and children made vulnerable (OVCs) by HIV/AIDS. It is a home within the community that employs a surrogate mother from the community, to provide care to the orphaned children. The bulk of the OVC work is undertaken by the home based carers, who have received further training in Child Care.

The third core function of the COC is Palliative Care. According to the World Health Organization (2001)), the term Palliative Care denotes a programme of care for those patients whose needs are primarily for comfort and relief, as medical cure is not possible. Care aims primarily to reduce or abate physical, medical, spiritual and psychosocial symptoms of advanced disease. It acknowledges death while focusing on life.

One such response to HIV/AIDS Palliative care is the introduction of 'step-down' facilities, such as The Dream Centre, located in Pinetown - a suburb close to Durban. A 'step-down' facility, in the context of the health setting, can be described as a non-hospital based continuum of care facility for the HIV positive patient. It focuses on

the nutritional, psychological and physical comfort of HIV positive patients and encourages family intervention and support. It is hoped that such facilities will serve as an intermediary between hospital and home-based care. Sadly, little recognition has been given to the role that volunteers have played in home based care settings.

The COC is a typical example of an integrated home based care model which works by linking all service providers with patients and their families in a continuum of care process. Situated on the premises of the St Mary's Hospital is advantageous to the COC in that a percentage of the COC's patients, living in the catchment area serviced by the St Mary's Hospital, can easily access medical services. Networks with other medical facilities such as the local health clinics and surrounding hospitals further enhances the COC's referral systems. The care provided by the COC is largely based on home based care and palliative care. The patient and the family are the focus of care and support.

4.6 WHO IS ELIGIBLE TO JOIN THE COC PROGRAMME?

Any person that is chronically ill, disabled or unable to care adequately for him/herself (elderly/orphans) and lives in one of the eleven COC areas of operation, is eligible to access services from the COC.

4.7 PATIENT REFERRAL INTO THE COC PROGRAMME

There are essentially two ways in which patients get referred into the COC programme. These are outlined below:

4.7.1 Patient referral from the Hospital

Upon admission to the St Mary's Hospital, a COC staff member (area coordinator) visits the wards to establish who the new patients are and whether they would require home based care, once they are discharged. This process is referred to as Patient Assessment. The COC staff member informs patients and/or relatives about the home based care services provided by the COC. Home based care is only available in the eleven areas that COC serves. Those patients who reside within those eleven areas, and who indicate that they would require home based care, are interviewed again by the COC Staff member, upon their discharge, to obtain residential details. Those patients not living in the COC's area of operation are referred to a local home based care program, if one exists. The COC staff member contacts the community facilitator and /or the home based carer to inform them of the new patient's details. The patient is formally enrolled into the COC Program

4.7.2 Patient referral from the Community

Patients' relatives or concerned members of the community approach home based carers directly for assistance for patients. Either the community facilitator assesses the patient or the home based carer who informs the COC. A patient card is made and the patient is formally enrolled into the HBC Program. Many patients enrolled into the COC programme are HIV positive, and chronically and terminally ill.

4.8 REponsibilities of a Home Based Carer of the COC

Home based carers offer their services especially to people infected or affected by HIV/AIDS as well as patients with other chronic diseases, helpless patients, disabled persons. The aim of COC is to provide respectful, sensitive and holistic home based care service to the chronically and terminally ill; the disabled; those people living with HIV/AIDS; and those who can no longer care for themselves.

4.8.1 The Role of the COC Home Based Carers

Patients are only visited by home based carers who have completed the required training. Home based carers are encouraged to commit themselves to a minimum of three hours service per week, for a period of at least one year. They work within their own area of residence, to minimize transport costs. Home based carers are not required to provide food, transport fees, financial or material support to patients they serve, except if the aid was given by the COC for the patient. They are not required to take over guardianship of orphaned children or neglected and confused adults. Identity badges, made by the COC, which details the home based carer's identifying and COC registration details, have to be worn when working in the communities. Home based carers are requested to report to their supervisors (community facilitators) at least twice a month. They are requested to attend the area meetings regularly.

4.8.2 Duties of Home Based Carers

Home based carers are encouraged to become integrated in the community, by meeting with local clinic staff, community leaders, and other organizations who work in the area. Their duty is to visit the sick patients in the patients' home and to provide

home based care; to teach patients and caregivers the relevant skills to enable them to be cared for at home (hygiene, nutrition, importance of compliance with medication, etc); to use infection control whenever necessary; and to teach patients and significant others about transmission of HIV/AIDS. In the absence of a primary caregiver within a home, the home based carer is expected to accompany patients to the clinic, for treatment, when necessary. The home based carer is required to be familiar with the relevant referral networks for patient. These may include Social Workers; Para Legal Officers; and/or Social Grants pay points.

4.8.3 The Scope of Practice of Home Based Carers

- Take the patient/ family history (Genogram)
- Assess the patient's Activities of Daily Living (ADL)
- Assist the patient and educate the family with /about personal hygiene and infection control
- Examine and treat the skin condition appropriately (presence of rash, wounds, pressure areas)
- Examine and treat the mouth condition appropriately (sores)
- Overall general appearance of the body (notice wasting, obesity, deformity etc), and to make the appropriate referral.
- Education of the patient and the primary care givers on nutrition.
- Provide basic education on social services (grants, documents to be kept)
- Provide basic counseling of patient and family; and provide emotional support
- Pastoral care of the patient and the family
- Develop a care plan by working together with the patient and the family

- Encourage compliance with pharmaceutical treatment e.g. Tuberculosis drugs.
- Basic record keeping of patients' progress and reporting to the COC Area Coordinator regularly.

4.9 COC NETWORKS

Within the COC context, the general means of recruitment is through the local Councilor's office and through 'word of mouth'. The COC finds itself in a fortunate position in that it has a steady flow of prospective home based carers waiting to join the programme. COC networks with local NGOs and CBOs that work in the home based care field. Some of those organizations are: Sinosizo Home Based Care and OVC Programme; St Clements Home Based Care Project; Hope and Family Life Foundation; and The Dream Center. The Center also works closely with the Mariannhill Diocese to assist in educating community members on HIV/AIDS.

The HIV/AIDS Community Support Projects fall in line with the KwaZulu Natal Department of Health HIV/AIDS Home Based Care Program and follows the referral system as stipulated by the Government under the District Health System. Ongoing networking takes place between other projects affiliated or run by St. Mary's Hospital: Ithemba-Anti Retroviral Wellness Clinic for PLWAs; Mother-to-Child-Transmission-Program (MTCT); the Highly Active Anti Retroviral Treatment (HAART) study.

4.10 ORGANIZATIONAL VOLUNTEER STRUCTURE OF COC

The following figure shows the organizational volunteer chart that exists at the COC.

The Area Coordinator is an employed staff member who supervises the care given to the patients by the community facilitator and the home based carers, who are unpaid volunteers. Currently, the COC has eight Area Coordinators in its employ. Interestingly, they have been upgraded and are now employed from the pool of home based carers of the COC. Although they are formally employed, they still volunteer as home based carers in their spare/personal time (COC Fact Book, 2005).

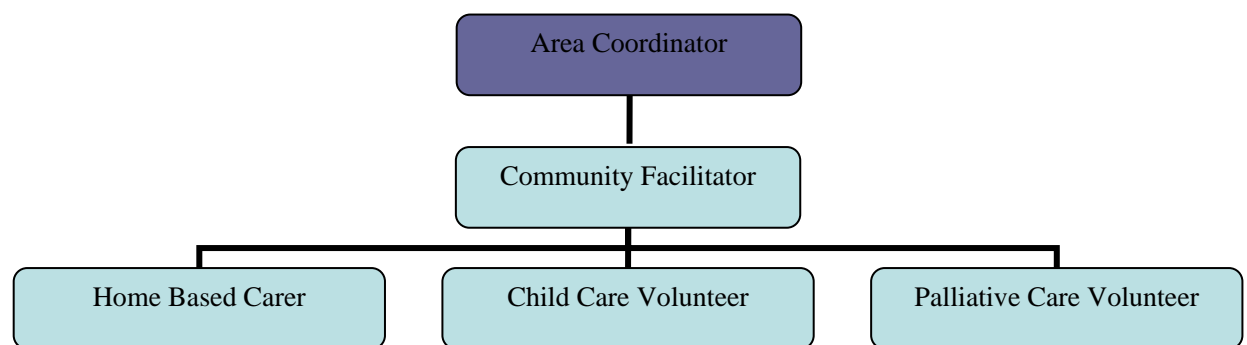


Figure 2: Organizational Volunteer Chart of COC

4.11 INTERNATIONAL VOLUNTEERS

COC has hosted a number of international professional volunteers. Some of the specialized skills brought to the COC included training modules in basic Physiotherapy, Palliative Care, and Child Care.

4.12 COC OBJECTIVES FOR THE NEXT THREE YEARS (2006-2008)

The COC strategic plan focuses on five main areas. The first object is the home based care component of the programme that seeks to: enroll approximately 1500 patients and their families into the programme; to train 300 additional home based carers and to upgrade fifteen home based carers to community facilitators.

The second objective is the Palliative Care component of the programme that seeks: to train 60 active and trained home based carers as Palliative Care Volunteers per year; to provide them with additional skills in order to support patients with incurable conditions, inside and outside the hospital; and to prepare and support patients and relatives during the progression of disease, right through to the terminal phase of the disease (death), and thereafter, if required.

The third objective is the OVC component of the programme that seeks to: to train 60 active and trained home based carers as Child Care Volunteers and to provide them with additional skills so they may respond to the needs of the children in the communities; to maintain the existing eight psychosocial support groups in the schools and to establish two more per year per funding cycle; and to maintain the existing two drop-in centers and to establish two more per year, per funding cycle.

The fourth objective is to continue with community awareness initiatives by raising awareness on topics such as HIV/AIDS, TB, communicable diseases, accessing social grants, nutrition, and hygiene, in the communities.

The fifth objective is to provide an opportunity for eighteen especially dedicated and long serving home based carers/palliative care volunteers/child care volunteers an opportunity to undergo nursing training.

SUMMARY

As can be seen, the core functions of the COC depend heavily on having a team of dedicated and committed volunteers. The COC has in place systems and varied training opportunities to both increase the capacities of the home based carers, and to increase the quality of care to the patients.

While the COC has a large volunteer base, research on their volunteers is conspicuously lacking. There appears to be no documented recordings on what motivates the home-based carers to volunteer and what their expectations of the COC are. It is hoped that by undertaking this study, the COC will be enlightened on the factors that motivate its volunteers to stay on in the programme. It is hoped that the COC can learn lessons on how to sustain its large volunteer base and to improve on its existing structures/programmes. On a broader level, it is hoped that other organizations that utilize services of home based carers, will be able to find use and relevance from this study.