

**CHALLENGES EXPERIENCED BY COMMUNITY ORGANIZATION
IN THE PROVISION OF HIV/AIDS HOME BASED CARE**

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A mini-thesis submitted in partial fulfillment of the requirements for the degree of Masters in Human Ecology in the Department of Human Ecology, Faculty of Community and Health Sciences, University of the Western Cape.

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November 2010

CHALLENGES EXPERIENCED BY COMMUNITY ORGANIZATION IN THE PROVISION OF HIV/AIDS HOME BASED CARE

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KEYWORDS

Challenges

Community organization

Home based care

HIV/AIDS

Voluntary service

Role

Training

Gender equality

Risk

Umtha Welanga



ABSTRACT

In many developing countries including South Africa, there is an overwhelming number of people infected with HIV/AIDS in the hospitals, which the health care workers are unable to cope with. Therefore, an urgent need to develop alternative community based activities such as support groups, home based care programs and placement of orphans, for the provision of social health care services to the HIV client, arises. However, a deeper understanding of the challenges facing community organizations when providing home based care is crucial and necessary in order to formulate effective and relevant care services.

The aim of the study was to explore the challenges faced by Umtha Welanga Community Organization (UWCO) in the provision of HIV/AIDS home based care. The objectives of the study were to assess the current home based care of the UWCO and to explore the challenges that community based organizations have to face when providing care services to people being infected and affected by HIV/AIDS. The research design undertaken was the case study of UWCO. The qualitative approach with in-depth interviews with the management staff and home based caregivers was utilized. Data analysis began immediately after the interviews by transcribing and translating the audio-taped data. Thematic analysis was used in which data was coded and categorized.

The findings of the research indicated that the home based care programme assists PLWHA clients in their natural home setting. All home based carers work voluntary and get supported by the organization as well as by the department of social development and health such as the social workers. Finances appear to be, both for the organization and the home based carers, a huge hindrance. Research indicated that the organization experiences various challenges to provide the service to their community. It is recommended that Government must ensure that home based care workers get recognition, credit and support for their valuable contribution. Training for HBC employers needs to be extended to expose and add more skills. This will ensure that they are equipped for their tasks. Home based care workers must become registered and paid better salaries by the government.

DECLARATION

I declare that, the work contained in this thesis is my own original work and that I have not previously in its entirety or in part submitted it at any University for a degree, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

Rendani Marcia Ramuhaheli

November 2010

Signed: -----

Date: -----



DEDICATION

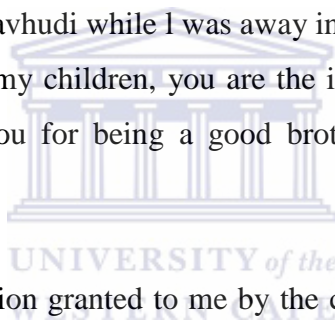
This thesis is dedicated to my late mother Phyllis Mutangwa Makhadi Ramuhaheli. My father John Ramaano Sigidi, my brothers and sisters, thank you for the support and encouragement you have given during this research journey.



ACKNOWLEDGEMENTS

Glory and praise be to the highest King Jesus Christ who was the source of my strength. I thank God for granting me faith to endure all the pain and suffering during difficult moments. It would not have been possible to complete this research without the leadership and guidance of the Holy Spirit. I am absolutely indebted to many people who have, in one way or another, contributed to the fulfilment of the present research paper.

Deepest gratitude to my family, my father, John Ramaano for his support, morally and financially. I also acknowledge my late mother Phyllis Mutangwa Makhadi and grandmother Tshinakaho Nyakhuhu Makhadi for their love and support. This degree was completed in your honor and remembrance. Mutshekwa Ndou, thank you for taking care of my children, Tendani and Wavhudi while I was away in Cape Town. I salute you for being a good mother to me. Both my children, you are the inspiration and reason I studied this degree. Alugumi, I thank you for being a good brother to me. My sisters, Ngodiseni, Livhuwani and Barbara



I also appreciate the permission granted to me by the coordinator and founder member of Umtha Welanga Community Organization in Khayelitsha, Vivian Nombvuyo Mciteka. I am very thankful for allowing me to conduct the study at your organization. I am also thankful to the home based care workers of UWCO who agreed to participate in the study. You have made this study possible through opening and sharing of your experiences.

I wish to extend my sincere gratitude to my supervisor, Dr C Erasmus for her guidance, understanding and excellent ongoing support. Special thanks to the entire staff in the Department of Human Ecology for giving me a hand, advice, guidance and support. I thank my lecturers, particularly the Research Method lecturer, for her encouragement and motivation. You made me believe in myself.

LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
CBO	Community Based Organization
CHBC	Community Home Based Care
FBO	Faith Based Organization
HIV	Human Immunodeficiency Virus
HBC	Home Based Care
NGO	Non -governmental Organisations
PLWHA	People Living With HIV/AIDS
UWCO	Umtha WeLanga Community Organization
UN	United Nations
UNAIDS	United Nations Aids
UNICEF	United Nation Children's Fund
USAID	United States Agency for International Development
WHO	World Health Organization

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CHAPTER ONE

STATEMENT OF THE PROBLEM

1.1 INTRODUCTION

Globally, the total number of people living with HIV/AIDS in 2008 was 33, 4 million with 31, 3 million adults, 15, 7 million women and children under 15 years 2, 1 million (UNAIDS, 2009). Approximately 1, 9 million people living in Sub-Saharan in 2008 became newly infected with HIV, bringing the total number of people to 22, 4 million. The Sub-Saharan region also accounted for 72% of the worlds Aids-related deaths in 2008 (UNAIDS, 2009). South Africa is one of the countries around the world with the highest number of HIV/AIDS cases. In 2008, an estimated 5, 7 million South Africans were living with HIV/ AIDS (UNAIDS, 2009). The government of South Africa has an aim to utilize an integrated plan for care, management, treatment and support by developing social responsibility and action for those living and affected with HIV/AIDS (Page, Louw & Pakkiri, 2006).

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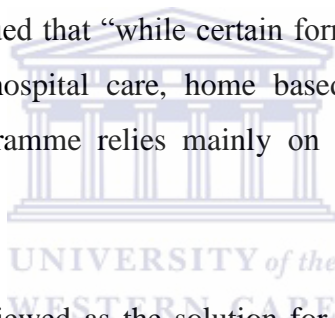
1.2 BACKGROUND

Civil society organizations has been at the forefront of responses to AIDS in many parts of the world, and some of the clearest successes in confronting the epidemic have been linked to the active role played by local level actors such as home based carers to care and support the affected, infected people and households including orphaned children (Birdsall & Kelly, 2007). In most cases, of the people living with HIV in South Africa, the care responsibility is provided at household level by family members, through home based care operating under the community based organization (CBOs) and faith based organization and particularly by women and girls (Ogden, Esiemen & Grown, 2004).

In response to the growing demands the HIV epidemic has placed on people and communities, hundreds of lay individuals have been trained as community health workers to provide home based care to the sick and dying HIV/AIDS clients (Johnson & Khanna,

2004). Home Based Care is an innovative approach to meet the needs of People Living with HIV and Aids (PLWHA) in resource limited setting (PathFinder, 2006). It is the provision of health services by formal and informal caregivers in order to promote, restore and maintain a person maximum level of comfort, function and health including care towards dignified death (National Department of Health, 2001). Community Home based Care (CHBC) is the care and support that people living with HIV/AIDS and other chronic illness receive in their homes, through families and their communities (International Federation of Red Cross and Red Crescent Societies, 2008).

As more people become infected with HIV, hospitals, hospices and other institutions for care experience burden of caring as a result of shortages of hospital beds, insufficient health personnel, lack of treatment and drugs, crowded hospitals and costs of institutional care (WHO, 2000). It is argued that “while certain forms of home based care may be less expensive than in patient hospital care, home based care requires the investment of resources, even if the programme relies mainly on volunteers” (Russell & Schneider, 2000:12).



Home Based Care is now viewed as the solution for caring and supporting people with HIV/AIDS and affected families (Sadler, Bahwere, Guerrero & Collins, 2005). It has been argued that in Southern Africa, home based care for HIV/AIDS clients is being promoted as a cheaper substitute to hospital care by the policy makers (Ankitola, 2008). However, the author further argued that cheaper forms of care can only be drawn by assessing all of costs, benefits and utility derived by all stakeholders in home based care. Families are regarded as the basic providers of care to the sick, however nowadays, roles have changed and women, who have been traditionally regarded as givers of the care, are pulled into the paid labor force by economic necessity or personal desire (Ncama, 2007).

Home and community based care provides a supportive, familiar environment of home setting for care, and it can provide a cost effective option that enables stabilization of individuals chronic conditions (National Association for Home Care and Hospice, 2006). Home based care calls upon the resources, skills, time, energy and funds of community

organizations and government. No single entity is able to meet the total requirements and challenges of home based care.

In a study conducted in KwaZulu-Natal, South Africa, it was documented that most of the care programs in South Africa (even on behalf of the government) rely on unemployed volunteers for affected communities, who are usually female and unsalaried or in few cases, paid in a small stipend (Campell, Nair, Maimane & Sibiya, 2007). They further argued that this voluntary work aggravates their poverty, as many care givers share food and material goods with the patients they visit, spending long days working free of charge instead of looking for paid jobs and which is a form of exploitation.

Community and home based care is generally less recognized and undervalued by both the public and private institutions (Schneider, Hlope, & Van Ransburg, 2008). However, the Department of Social Development in the Republic of South Africa supports organizations that offer range of services to individuals and families infected and affected by HIV/AIDS. These organizations must provide home based /community based care to ensure that basic needs of people living with the HIV virus are met. It is argued that when there is a sick or dying person, someone has to take responsibility of caring which can be motivated by love, sense of duty and alternatively because of lack of options (Ogden, Esimen and Grown, 2004). There is no doubt that there is a great need for services and support provided by home based care providers to people who are living with HIV/AIDS.

1.3 RATIONALE OF THE STUDY

In many developing countries including South Africa, there is an overwhelming volume of people infected with HIV/AIDS in the hospitals which the health care workers are unable to cope with. During the mid to late 1990s, when programmers and policy makers realized that the public sector was not going to manage AIDS-related morbidity, they began considering ways to shift the focus of clinical care from health services to the community because it was seen as a better strategy to care for the patients by their own families and

friends with dignity (Ogden *et al*, 2004). Limited health care services, shortage of hospital beds, inadequate number of medical, nursing and allied health professionals in the public sector, lack of resources for treatment and drugs, cost of institutional care, hospitals which are crowded and often unsuitable for managing patients with terminal or long term disease (Ankitola, 2004) highlighted the need for informal caregivers (mostly family members & friends) (Campell, Nair, Maimane & Sibiya, 2008).

Therefore, an urgent need exists to develop alternative community based activities such as support groups, home based care programmes and placement of orphans for the provision of social health care services to the HIV/AIDS client. Home based care is important to the person with Aids because it allows them to get care in their own environment, they can still partake in family activities and feel that they belong and it makes it easier for them to accept their condition (WHO, 2000).

1.4 PROBLEM STATEMENT

The aim of the study was to explore the challenges of providing HIV/AIDS home based care services by the Umtha Welanga Community Organization (UWCO).

1.5 OBJECTIVES OF THE STUDY

1.5.1 To examine home based care provision of the Umtha Welanga Community Organization

1.5.2 To explore the challenges faced by UWCO in the provision of HIV/AIDS home based care.

1.6 OPERATIONAL DEFINITIONS

For the purpose of this study, the following operational definition serves as a starting point:

Community organization- is an organization formed to promote the interest of a particular community whereby people are brought together in a common self interest and normally takes places under the umbrella of non-profit organization that reaches out and

engages people to action which is often times paid or volunteer help to advance community interests (Minieri & Getso, 2007).

Care- refers to full range of activities undertaken by family and non-family members including psychological support (emotional and spiritual), custodial care (cooking, cleaning, feeding, helping to the toilet and mainstream of the remedies and treatment) and the subtle elements such as love and healing. Home care combines health care and support services to help homebound sick or disabled people continue living at home as independently as possible and they assist with medical needs, nursing services and physical therapy, while non medical services includes helping with daily chores, housekeeping and good conversation (Scott, 2006).

Home based care (HBC) - is the provision of basic nursing care needs by formal and informal caregivers to people in their own homes. The service is administered to people who are having mental, emotional, physical and social needs. The care is meant to restore and maintain the individual's level of comfort, function, including care towards a dignified death (Department of Health, 2001).

Community Home Based Care (CHBC) - is defined as any form of care given to sick people in their homes (WHO, 1999). The goal of CHBC is to provide hope through high-quality and appropriate care that helps family caregivers and sick family members to maintain their independence and achieve the best possible quality of life (WHO, 1999).

Human Immunodeficiency Virus (HIV) infects cells of the immune system, destroying or impairing their function. Infection with the virus results in the progressive deterioration of the immune system, leading to "immune deficiency." The immune system is considered deficient when it can no longer fulfil its role of fighting infection and disease. Infections associated with severe immunodeficiency are known as "opportunistic infections," because they take advantage of a weakened immune system (WHO, 2010).

Acquired Immunodeficiency Syndrome (AIDS) is a fatal clinical condition that results from infection with HIV, which progressively damages the body's ability to protect itself from diseases (FAO, 1997).

1.7 ETHICAL STATEMENT

Permission to conduct the study was granted by the Higher Degrees committee of the University of the Western Cape prior to conducting the research. Written consent was obtained from the participants of Umtha Welanga Community Organization executive staff and home based care workers before resuming with the research. The researcher entered into an agreement with participants, where the purpose and nature of the research was clarified and well explained. The participants were also informed that they have the right to refuse participating in the study. Participation in the study was voluntary and respondents had the right to withdraw from the study if they were not comfortable to continue. All the participants were notified about the risks and benefits of the study.

They were assured that confidentiality was guaranteed and no personal information would be disclosed unless permission was granted by participants. The appropriate informed consent form was signed by participants.

1.8 OUTLINE OF THE STUDY

Chapter 1: This chapter provides an introduction and background of the current study. It includes the problem statement, objectives of the research and rationale of the study. The relevant terms used in the research are defined, followed by the ethical statement.

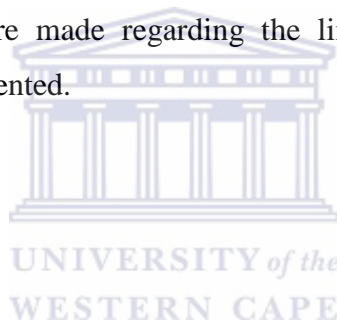
Chapter 2: Chapter two presents a review of the literature that is relevant to this study. The aim was to understand what other scholars have achieved regarding the challenges facing community organization in the provision of home based care. The following sub-topics were reviewed: community organization, training of caregivers, financial

implications, physiological demands, psychological /emotional demands, voluntary activity and challenges experienced.

Chapter 3: In this chapter the research methodology, research design, data collection and data analysis procedures, ethical considerations and limitations of the study area are discussed. Data was collected by using face to face interviews and simple observation.

Chapter 4: This chapter presents the results obtained from the data collected through the in-depth interviews and observation. The analyzed data was discussed according to the aims of the research. The findings are debated and compared with related studies.

Chapter 5: The summary of the findings, conclusions and recommendations are given in this chapter. Comments are made regarding the limitation of the study and a final summary of the study is presented.



CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter reviews the literature related to the study on the challenges of providing HIV/AIDS home based care services. The following literature review focuses on studies done globally and in Sub-Saharan Africa with relation to the issues on home based care, community organization, volunteer work, education and training, financial implications and other challenges.

2.2 HOME BASED CARE OR COMMUNITY HOME BASED CARE

Home based care (HBC) is the provision of health services by formal and informal caregivers in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death (National Department of Health, 2001). It can also be regarded as the care and support that people living with HIV/AIDS and other chronic illness receive in their homes, through families and their communities (The International Federation of Red Cross and Red Crescent Societies and National Societies, 2008). Community home based care (CHBC) is defined as the care given to an individual in his/her own environment (home) by his/her family and supported by skilled welfare officers and communities to meet not only the physical and health needs, but also the spiritual, material, and psychosocial needs (Mohammad & Gikonyo, 2005).

HBC is an innovative approach to comprehensively meeting the needs of People Living with HIV and Aids (PLWHA) in a resource-limited setting (PathFinder, 2006). It was designed as a way of implementing effective and inexpensive community based care and support and to cater for all incurable conditions such as cancer and not only HIV/AIDS (Kenyon, Heywood & Sonway, 2002).

Home- and community based care takes many forms, but is typically provided by relatives, friends or community volunteers working for non-governmental organizations and supported to a greater or lesser extent by health professionals (UNAIDS, 2000). HBC is usually carried out by informal caregivers who have been trained as community health workers to provide home based care to the sick and dying HIV/AIDS clients (Johnson & Khanna, 2004). Generally, “people often think that those who provide care are trained doctors, nurses and other health care personnel, however, a family member or friend is often qualified to assist in daily activities and often takes on the informal role of primary caregiver” (Scott, 2006:1). HBC workers are responsible for paying visits to the clients and families to provide care and advice and supply them with drugs and materials for symptoms management that can be handled in the households (UNAIDS, 2008).

HBC is viewed as the solution for caring and supporting people with HIV/AIDS and affected families (Sadler, Bahwere, Guerrero & Collins, 2005). It is reported that home based care is cheap and acceptable to the family and patients; it can produce care that respects cultural practices and minimize the costs of family attendance to the hospital (Harding & Higginson, 2005).

Home and community based care provides a supportive, familiar environment of home setting for care and can provide a cost effective option that enables stabilization of persons’ chronic conditions (National Association for Home Care & Hospice, 2005). Home based care calls upon the resources, skills, time, energy and funds of community organizations and government as no single entity is able to meet the total requirements and challenges of home based care. Effective and cheaper home based care relieves the hospital burden and has social benefits for the client and their families (Nsutebi, Walley, Mataka & Simon, 2001).

However, community/home based care and support should not be used as a replacement to the care and support provided by the formal health sectors but it should be viewed as one element in a co- coordinated and integrated continuum of care (Russell and Schneider, 2000). It is revealed that community home based care in Zambia, has minimum support

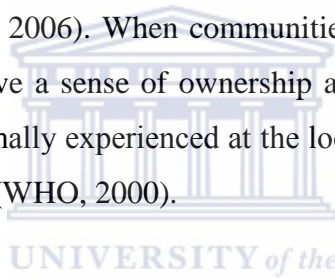
from the health sector and that carers, clients and supervisors alone are not sufficient for the development, supervision and support in the delivery of home based care (Chaava, 2005). In South Africa, the promotion of home based care has been made a national government policy to cater for HIV/AIDS and other terminal illness (Ankitola, 2004). Home based care and community based care can operate effectively to provide the quality care and support services for the clients and families when operating under the community based organization.

2.2.1 Community Based Organization

Community based organization (CBO) is an organization that provides social services at the local level and is a non-profit organization whose activities are based primarily on volunteer efforts such as labor, material and financial support (Chechetto-Salles & Geyer, 2006). It provides significant HIV care, support and treatment to people infected and affected by HIV in Africa and has shown that it can provide quality activities, and sometimes as a supplement or replacement to public sector services (UNAIDS, 2005).

Families and communities are the first line of response to the HIV/AIDS epidemic (UNICEF, 2004). Community based organizations in the response to HIV/AIDS, have played a crucial role such as prevention, treatment, care and support as well as working to create a conducive social, political, legal and financial environment needed to effectively respond to the epidemic (UNAIDS, 2010). Community based organizations and NGO's fulfil an important role in helping families and communities to cope with HIV/AIDS (WHO, 2005). There are many community based organizations which are already offering critical care and treatment services such as home based care, palliative care and generation of income (UNAIDS, 2005). However, the crucial role played by the community based organization has not been widely recognized (UNAIDS, 2005). Community based organizations should not be expected to shoulder the majority or full responsibility for what is really an obligation of the state, but the CBO's must aim to develop partnerships with the government, private sector, schools, communities, families and individuals to ensure effective service delivery in the fight against HIV (UNAIDS, 2009). The aim is to provide care, support and assistance in the prevention of HIV/AIDS (USAID, 2002).

The purpose of the home based care community organization is to provide palliative care, which is intended to comfort and support individuals and families living with a life threatening illness such as HIV, in order to meet the physical, psychological, social and spiritual needs of ill people and caregivers (WHO, 2002). Home based care is expected to reduce the pressure on hospital beds and other resources at different levels of services, which evokes feelings of ownership and accountability (UNAIDS, 2010). This allows people to spend their days in a familiar surrounding and reduces isolation and allows patients the right to decide about care within his or her own environment (WHO, 2002). Furthermore, home-based care programs for most resource-poor settings play a significant role in providing access to comprehensive palliative and supportive care for a large proportion of individuals and families affected by the HIV disease (US: Department of Health and Human Services, 2006). When communities are involved in the role of HBC, the more likely they will have a sense of ownership and responsibility (UNICEF, 2004). The impact of CBO's is normally experienced at the local level, especially in the homes of ill people and the caregivers (WHO, 2000).



The involvement of community based, non-governmental and faith-based organizations has been promoted as a cost-effective strategy that can rapidly expand HIV care services (USAID, 2002). A CHBC program is used as another strategy by many African countries to respond or shift care of people living with HIV/AIDS into family and communities and such responsibility is carried out by women and girls (Ankintola, 2000). In South African countries, the majority of community programs or projects on HIV/AIDS are focused on home based care services rendered by community organizations or agents and often by the volunteers working for these organizations or agents (Ankitola, 2004). The aim of CBO is not to replace the work performed by the public health sector but to mobilize the response to the HIV situation, while closely working with the public health sector so that the efforts of both parties are reinforced (UNAIDS, 2005). Moreover, an important asset of the CBO is the volunteers who willingly offer their time and energy to care for the families that are infected and affected by HIV/AIDS.

2.2.2 Voluntary work

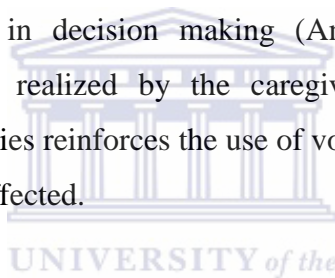
Volunteers in South Africa play a significant role in the provision of care for people living with HIV/AIDS (Ankitola, 2008). Home based care is carried out by volunteers who are from the affected communities (Akintola, 2004) 'which are normally not family of the client, but are recruited from AIDS affected communities' (Akintola, 2008:358). Volunteers are responsible for carrying out various activities among HIV/AIDS affected families which is primarily to assist in relieving the burden that caring for People Living With HIV and AIDS (PLWHA) has on the affected families, to show love and compassion, providing support through praying and encouraging them (Ankitola, 2005).

The various activities that volunteers provide include basic AIDS teachings and general home based care support for sick people. They also play a significant role of mediator, counsellor and general caretaker under the difficult circumstances; most of them receive no salary payment and have to spend their own money to assist their client (Campell, Nair, Maimane & Sibiyi, 2007). It has been pointed out that volunteers, who are from poor settings, are driven by hope that it will lead to paid work or some other benefits. If these paid jobs do not materialize, it can be frustrating for volunteers (Friedman, 2002). Although volunteerism will continue to be encouraged and should volunteers be employed more than a few hours a week without remuneration, volunteers should not be misled into believing that they will necessarily get paid work (Schneider, Hlope & Van Rensburg, 2008). A study conducted in Kenya, has shown that volunteers are not paid for their time, but the organization provides some volunteers with training and allowances to cover necessary transportation (Thurman, Hoffman, Chatterji & Brown, 2007).

It has been documented in a study conducted by Cunningham, Sanchez, Heller & Sohler (2007) that those undertaking voluntary home based care responsibilities, sometimes have to walk long distances under the hot sun to get to their clients. It is further highlighted that volunteers sometimes are discouraged and find it unbearable to continue with their duties such that some consider quitting (Ankitola, 2008). It was also argued that if home based care programs are to be successful in playing a vital role of care and support of people with

AIDS, volunteers should be adequately remunerated as well as to have access to support structures, which encourage effective service delivery (Campbell *et al*, 2008).

Research conducted in Kwazulu Natal found that most of the care programs in South Africa (even on behalf of the government) rely heavily on the unemployed volunteers who are usually females and unpaid or, in a few cases, paid in stipends (Campbell *et al*, (2008). They argued that voluntary work worsened poverty as many caregivers share food and other material with the HIV clients they visit, spending long days working free of charge instead of looking for paid jobs. However, there is little knowledge concerning the benefits of volunteering among volunteer caregivers of people living with AIDS in the home-based care context in Africa, except for intrinsic rewards, such as improved self-esteem and health, and self-actualization, as well as extrinsic rewards, such as recognition, constructive feedback and participation in decision making (Ankitola, 2010). Regardless of the minimum material benefits realized by the caregivers, the high rate of HV/AIDS prevalence in poor communities reinforces the use of volunteer workers in care and support for the people infected and affected.



The notion that AIDS is a shared concern is reinforced by recruiting and training local volunteers in the provision of care (UNAIDS, 2005). Volunteers are also recruited to complement the services given by care workers by making themselves available as companions, collect medication and run shopping errands (Dept of Health, 2002). When community members volunteer their services in care giving, it provides organizations with more resources to achieve their goals in home based care to care for the HIV/AIDS client (Chinman & Wandersma, 1999). Therefore, community based organizations provide volunteers with incentives such as certificate of recognition, stipends and rewards, bonuses, encouraging words, food packages, toiletries, relieving somebody before s/he gets overwhelmed, allowing caregivers to work in turns (Kang'ethe, 2009).

When volunteer care workers are utilized, the cost and expenditure remain low, but also enables communities to work together in supporting each other (UNAIDS, 2000). Such volunteers are playing a significant role; however, strengthened systems such as

supervision and monitoring of their work by nurses and social workers, are needed for the appropriate support and management of community health workers (Scheinder, Hlope, & Van Rensburg, 2008). It has been argued that “certain forms of home based care may be less expensive than in patient hospital care and therefore home based care requires the investment of resources, even if the programme relies mainly on volunteers” (Russel & Schneider (2000:12). It is further pointed out that there is a need for trained professional inputs to supervise lay support skills given by volunteers and for the maximum capacity of patient care (Harding & Higginson, 2005). The Department of Social Development (2001) argued that volunteerism should be based on free will and not through obligation and/or forced into participating in the CHBC services. It is therefore necessary that these volunteers are given adequate training to provide excellent quality of care to AIDS patients and their families.

2.2.3 Education and Training

In the light of having the shortages of skilled trained professionals in Sub-Saharan Africa, a greater need for home based care to play a significant role in the provision of HIV/AIDS services and support is of supreme importance (Emmanuel, Reitschuler, Lee, Kikule, Merriman & Emmanuel, 2008). Training and education is critical to all caregivers who engage in home based care so that they care properly and thoroughly, and deliver competitive care services (Van Dyk, 2001). In many cases patients are discharged to households whose family members have no form of training about caring for people living with HIV (Ankitola, 2004). By attending training programs, home based caregivers become acquainted with the correct information and methods required to care for themselves and those with HIV/AIDS (International Federation of Red Cross & Red Crescent Societies, 2008). Training programs for home based caregivers should be continuous, community based, problem orientated, an experiential education process and a curriculum which is comprehensive, task orientated and outcomes based (Friedman, 2002).

It has been shown that ongoing training provides staff members with the necessary skills and knowledge to fulfil their roles as carers and to cope with the environment in which they work (UNAIDS, 2008). Home based caregivers, in contrast with professional health

care workers such as nurses, have low skills training or no training at all (Department of Health, 2002). Therefore, if they do not receive any training with regards to HIV/AIDS, they might not be able to protect themselves properly or prevent the spreading of infection from one patient to the other. Therefore it is important for home based caregivers to receive training and skills about proper health care while safeguarding them against possible infection.

Ankitola (2008) reported that volunteers felt that their training was very limited and not good enough to assist their clients. It was further reported that ‘caregivers often feel that they do not have the necessary knowledge and skills to assist home care clients properly, and are afraid they will cause more harm than good’ (Green, 1998:18). Inadequate trained staff, facilities, funding and appropriate infrastructure can prevent success of any intervention programme (Rabin, Brownson, Kerner & Glassgow, 2006). It is stated that there is lack of properly trained personnel across the CHBC mainly because of insufficient resources in conducting training, lack of expertise to carry out the training, lack of availability of guidelines and manuals and challenges in recruitment and retention of CHBC staff (Mohammad & Gikonyo, 2005).

On the contrary, volunteers trained in Entabeni, KwaZulu-Natal, reported that the training has added to their sense of personal motivation, confidence and credibility and add to the admiration they were shown by the community and by traditional leaders and raised levels or recognition of the value of their efforts” (Campell *et al*, 2008). They further revealed that the training has improved their level of knowledge and skills in terms of basic nursing since they are able to answer questions in relation with HIV. On completion of the training, participants were also able to train and empower other community members in spreading information about HIV/AIDS throughout the community (Campell *et al*, 2007). The training has also removed unnecessary fears about the various methods used to transmit HIV/AIDS from one person to another (National Department of Health, 2002). It is critical that volunteers must be empowered by ensuring that they receive proper training in program-decision making management and leadership rather than being recipients of instruction from the top (Campell *et al*, 2008). Furthermore, the biggest constraint facing

CBHC programmes is the funding of these programmes. To engage and retain caregivers, program need to provide an adequate salary and benefit packages (Mohammad & Gikonyo, 2005).

2.2.4 Financial Demands

The most challenging experience that faces CHBC is financing a programme over a long period of time. The responsibility of funding the program in some countries is carried by the government while in other instances it is done by international or national donor agencies, NGO's and Faith Based Organisations (WHO 2002; Antikola, 2008). It has been reported that the stability of finances in a community home based care organization is very critical in creating a secure work environment for staff, most of who have families and other commitments (UNAIDS, 2008). Home based care is time and resource consuming and has difficulties such as travel costs and travel time (Campell & Foulis, 2004). Lack of funding jeopardizes the sustainability of the community organizations, thus leading to a dependence on volunteer caregivers (Browning, 2008).

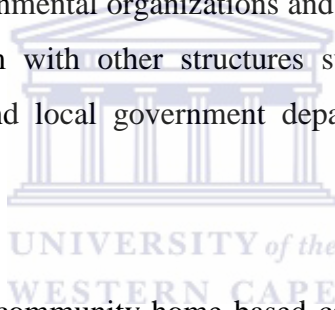
Home based care is probably the only workable solution in the South African context, but it should not to be regarded as a cheap resolution to tackle the AIDS epidemic (Ankitola, 2008). If this is going to be the South African Government's solution of dealing with the Aids issue, then there needs to be adequate funding and remuneration for home based care workers. While there are a few community based organizations that receive funding from the Departments of Health or Social Services at national or provincial level, there are several informal community based care organizations providing a range of health care without remuneration (Campell *et al*, 2000).

Salaries paid to the home based care givers vary from organization to organization and from hospice to hospice (Department of National Health, 2002). Most of the caregivers at Kange Program in Botswana complained of receiving no incentives or any form of payment for their care giving roles and they have indicated that they do the work because they are blood relatives of the clients (Kang'ethe, 2009). Furthermore, it is also revealed that some organizations have fears that they can lose their staff for better employment

opportunities (Kang'ethe, 2009). Besides committed and well trained volunteers, CBHC organizations also require effective support systems to provide adequate care to its clients and their families.

2.2.5 Support systems

Volunteers are playing a significant role in home based care; however, strengthened systems are needed for the appropriate support and management of community health workers (Scheineider, *et al* 2008). It has been emphasized that home based care cannot operate as a single entity but must be integrated with other structures in order to operate effectively in terms of service delivery (Department of National Health, 2002). The success of CHBC programs can only be guaranteed when there is active support and participation from government, non-governmental organizations and communities and must therefore be linked to or form a system with other structures such as hospice home based care, community organizations and local government departments (Mohammad & Gikonyo, 2005).

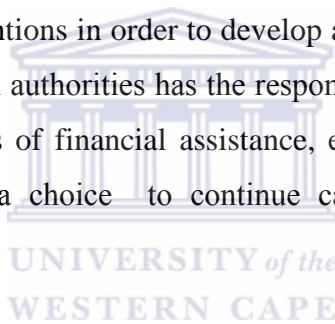


Research has indicated that community home based care in Zambia, received inadequate support from the health sector, and carers, clients and supervisors alone are not sufficient for the development, provision of supervision and support systems in the delivery of home based care (Chaava, 2005). In addition, home based care projects have limited involvement of governments in the provision of home based care services, appears to be the main reasons behind the low coverage of home based care programmes in Africa (Ntsutebi *et al*, 2001). They further argues that for an HIV/AIDS home care to expand effectively and have an impact on communities, government health services must have greater involvement, not only through verbal support, but through the formulation of policies, comprehensive plans and co-coordinating efforts of donors and service providers as this will have a multiplying effect on HIV/AIDS home based care coverage.

When the organization works in partnership, a weakness of one in a specific area can be complemented by the strength of another. Therefore an organization can improve its

services through learning from the expertise and experience of others (Department of National Health, 2002). There is great importance of collaboration amongst the local communities, other actors and agencies drawn from civil society, public support or private sector at the national or international level for the effective service delivery of home based care (Campell & Foulis, 2004).

There is lack of systematic support even in areas where support is relatively easy to provide, such as providing supplies for home based care (Birdsall & Kelly, 2007). Home carers at Kindlimuka in Zambia use plastic bags for gloves when they care for bedridden clients and contributions from such community members, many whom have very few resources, are an important element of support for the organization in its efforts to support orphans and people with HIV (Ntsutebi *et al*, 2001). Therefore, the need exists to combine state and community interventions in order to develop a coherent, inclusive care agenda. It has been indicated that 'local authorities has the responsibility to ensure that the carers are being taken care of in terms of financial assistance, emotional support, information and advice, practical help and a choice to continue caring or not' (Nocon & Qureshi, 1996:117).



Community organizations fulfil many roles in home based care for the HIV/AIDS clients. Whilst being committed to carrying out quality care to their clients, the caregivers face many challenges while delivering a service to their communities.

2.3 CHALLENGES EXPERIENCED BY COMMUNITY BASED ORGANIZATION

As it has been documented, home based care plays a vital role in the care of people living with HIV. As more people become infected with HIV, hospitals, hospices and other institutions of care, experience the burden of caring as a result of shortages of hospital beds, insufficient health personnel, lack of treatment and drugs, crowded hospitals and costs of institutional care (WHO, 2000). Home based carers execute complex roles in adverse conditions (Campell & Foulis, 2004). Challenges faced by care providers are great and vary from burn out and impoverishment, vulnerability to diseases, emotional and physical burden, which is devastating for those participating (Odgen *et al*, 2004).

Caregivers in Botswana were challenged by lack of community network support, inadequate sanitary and care packages, poor shelter compromising privacy, inadequate income and food for their clients, lack of motivation as their volunteerism does not attract any payment and inadequate health personnel to offer psychological support like counseling (Kang'ethe, 2009). Other challenges include lack of knowledge, skills and support both at individual and organizational level, physical and psychological burnout, stigma and rejection by caregivers (Campell & Foulis, 2004). In addition, it has been indicated that poverty, social cultural issues, inadequate health knowledge, lack of palliative services, transportation problems and feminization of the care giving have been challenges facing community home based care programmes in Botswana (Odek & Odo, 2007). Issues such as poor supervision, lack of appropriate incentives, and an unsupportive environment are the challenges experienced by caregivers (Schneider *et al*, 2008).

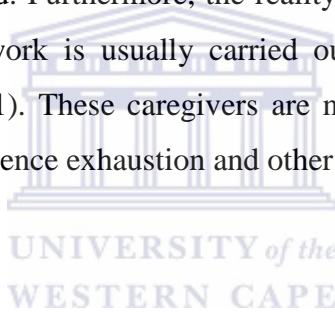
CHBC can be effective and affordable when there are good results in the health and social status of the clients, families and community as a whole. However, there are many challenges and limitations, which do not only affect the caregiver's ability to carry out their activities but can aggravate the condition of poverty and gender inequalities when conducting home based care services (Mohammad & Gikonyo, 2005).

2.3.1 Gender equality

Traditional gender norms result in women and girls providing care and it also creates social barriers to men and boys becoming caregivers (UNAIDS, 2008). The work of caring for HIV/AIDS clients is primarily a responsibility of women and girls (Ogden *et al*, 2004). This is usually taken for granted and undermined by the government and NGO's because it is usually viewed as the roles played by women to sustain their families, communities and nations (Ogden *et al.*, 2004). In many societies women are encouraged to put the well-being of others before themselves and are forced to cope with an overwhelming burden in their roles, both as principal carers and breadwinners (UNAIDS, 2008)

Gender discrimination undermines the rights of women and girls which results in girls dropping out of school to assist in caring for the ill relatives (UNAIDS, 2009). The provision of care should be addressed in gender sensitive ways (WHO, 1999). Women are the primary caregivers to the ill and spend active days and nights providing care to ill relatives, in addition to their general domestic chores (Opiyo, Yamaano, & Jayne, 2008). Glendinning, Arksey & Tjadends (2009) emphasized that care is gender based and women are the primary providers physically, emotionally and in long term care.

It has been documented that when women are engaged in care responsibilities, they become less involved in activities that have the potential to empower them and that the care work in the context of HIV/AIDS is very costly and it creates an unsustainable impact (Ankitola, 2004). Therefore, when the care work remains invisible to society, even the care workers are taken for granted. Furthermore, the reality of community or home based care basically means that care work is usually carried out by the unpaid and unsupported women (Ntsutebi *et al*, 2001). These caregivers are not only challenged financially, but also physically as they experience exhaustion and other turmoil.



2.3.2 Physical impact

Generally, assumptions are made that carers are capable and healthy individuals who have the knowledge, skills and attitudes to provide care. However, care giving is challenging both emotionally and physically with the potential to cause stress to carers (WHO, 2002). The physical burden and consequences of providing care for the people who have HIV/AIDS includes sudden and recurring head- and body ache, fatigue and muscle strain as a result of lifting patients (Ogden, et al, 2004). Physical exhaustion and fatigue result after walking long distances to the clients' homes (Ankitola, 2005). It was found that taking care of someone who is immobile can be challenging because carers may endanger their lives when assisting someone, perhaps heavier than themselves, with the task of getting someone from the bed or moving them around the home (Cunningham, *et al*, 2007).

Ankitola (2004) indicated that volunteer caregivers normally become the main care givers of sick people and their work can expose them to backache. These activities include nursing people with late stage-HIV which can be time consuming and tiring such as nursing an immobile client who needs constant care and attention. Furthermore, turning of the client to prevent bedsores, helping them to the toilet or to use the bed pan, washing and keeping them cool with a damp towel, cleaning and dressing sores and ulcers are the caregiver's responsibilities. Moreover, preparing food and drinks and helping to feed the client, providing company when the patient is feeling lonely, anxious or scared, helping to administer drugs and washing both client and their bedclothes (UNAIDS, 2000). It is critical that caregivers are given the emotional support since they are subjected to an array of trauma including confusion, crisis like abuse by the clients, sense of obligation and contracting infection themselves (Health and Development Networks, 2001). These caregivers need psychosocial support in eliminating fears, anxiety and depression.

2.3.3 Emotional and psychological impact

Emotional and psychological support or sometimes individual or group counseling plays an important part for everyone involved in care giving within homes (WHO, 2002). Caregivers reported that providing care in the home was a great challenge which drains them both economically and emotionally. Home care is a process which has its ups and downs brought about by the condition of the patient and his/her functional level and it calls for the total dedication on these responsibilities (Ndaba-Mbata & Seloiwe, 2001). Emotional and psychological support is known to enhance the quality of care to the client. Caregivers are also confronted with psychological and emotional challenges as well as unreasonable demands from both the client and his/her family (Ankitola, 2008). Caring may result in a sense of depression, anxiety, anger, frustration, excessive guilt, sense of lack of competence and self blame (WHO, 2005).

Kang'ethe (2009) reported that caregivers experience psychological problems due to neglect and abandonment due to care giving with minimal assistance from the patient's family members. Home based caregivers especially those visiting men who live alone may

experience fear of sexual abuse and rape (Cunningham *et al*, 2007). It is further highlighted that caring can lead to family conflict which affects time of establishing relationships with members of the family. Carers may also experience sleep disturbance, lack of appetite, psychosomatic complaints, loneliness, isolation and lack of social support. Therefore, such impacts of caring can influence carers' enthusiasm or ability to continue to provide care to the client (Cunningham *et al*, 2007).

It is critical that caregivers receive counseling to prevent burnout (WHO, 2002). Support groups help carers to share their experiences such as anxieties and concerns with other care workers since their work is emotionally draining and depressing (UNAIDS, 2000). Despite the negative experiences, 'volunteer caregivers derive intrinsic rewards related to self-growth and personal (emotional and psychological) development on the job. Furthermore, 'they also derived satisfaction from community members taking a liking to them and expressing a necessitated to their services. In addition volunteers also learnt over time how to love and be patient with the ill, which was seen as a great personal reward' (Ankitola, 2010:13). Besides the emotional and psychological impact on caregivers, they also have to deal with issues of poverty.



2.3.4 Poverty

Extreme poverty and poor food security in households with patients is one of the frequently documented challenges (WHO, 1999; UNAIDS, 2000(b); Ogden, *et al*, 2004). Most of the caregivers are people living in poverty and are constantly confronted with the practical reality of having to care for the clients who do not have food to eat (Ankitola, 2001). Home based caregivers encounter frustrating experiences of trying to access grants for the families and children (Ankitola, 2008).

Research conducted in Kwazulu-Natal found that most of the care programs in South Africa (even those funded by government) rely heavily on unemployed volunteers who are usually females and unpaid or in few cases paid in stipend (Campell *et al*, 2008). It is argued that voluntary work worsens poverty as many caregivers share food with HIV clients. Caregivers visit clients spending long days without remuneration, instead of

looking for paid jobs. The volunteer caregivers become more impoverished by Aids, since they must sacrifice their time that could be devoted to personal income generation to care for the sick, and draining their resources by providing for their neighbors (Ankitola, 2004).

It was also indicated that caregivers felt positive about the contribution they made, but found it difficult to cope with poverty and the complex problems they faced (Uys, 2001). It has been pointed out that volunteers, who are from lower socio-economic circumstances, are driven by hope that it will lead to paid work or some other benefits. If these paid jobs do not materialize, it can be frustrating to volunteers (Friedman, 2002). Moreover, caregivers' experience lack of recognition in the care works by both the government and community at large.

2.3.5 Lack of recognition

In general, caregivers lack recognition by the State and public; since the services they render are viewed as normal and an obligation to take care of sick family members (Ankitola, 2004). Furthermore, when the workload of caregivers increases, they also continue to go unrecognized for their important care giving services and remain marginalized (Ankitola, 2008). To address needs of carers, it is important that there is recognition of who the carers are and understanding of the services they provide (UNAIDS, 2008). However, in South Africa, this was recognized by the government in 2001 as being an effective care measure when it called for the establishment of home based care programmes (Ncama, 2005). Home based care work is the kind of service usually taken for granted and undermined by the government and the NGO's because it is usually viewed as the activities or role to be performed by women to sustain their families, communities and nations (Ogden *et al*, 2004).

Schneider, *et al* (2008) have shown that volunteers are dissatisfied with the lack of recognition to their work, being undervalued and experience exploitation without rights or benefits such as leave, maternity benefits and pension by healthcare authorities and communities. Carers should receive proper recognition for their work, experience,

knowledge and individual needs since lack of recognition to their services can affect carers in different ways (Ankitola, 2008). Caregivers have been taken for granted and yet they have been performing sterling and invaluable tasks of mitigating the AIDS pandemic through caring for the AIDS clients (Kang'ethe, 2010). The author also believes that it is a denial of informal caregivers' human rights not to be covered by compensation policies that cover other health service providers against any workplace occupational hazards and risks (Kang'ethe, 2010). Apart from lack of recognition, caregivers are vulnerable to various risks when conducting care services.

2.3.6 Risks faced by carers

The safety and security of the care givers are crucial in order to provide the optimum care to the clients. Home care workers are faced with considerable and huge tasks related to health and safety risks (UNAIDS, 2000). Health risks are created when caregivers come into close contact with client faeces, vomit and other bodily fluids and tuberculosis infection (UNAIDS, 2000). These risks are increased in a place where there is poor sanitation or no rubber gloves to wear during care services.

Criminal activities have become a significant threat to the safety of aid workers and such activities take different forms such as assault, hijacking and robbery (Kang'ethe, 2009). There are activities that involve lifting and moving those receiving care, working independently and exposure to infections, violence and general hazards such as trips to clients' homes by the caregivers to administer care services. Caregivers also experience the transport challenge when performing home based care, particularly when visiting clients who reside in remote areas.

2.3.7 Transport service

A holistic CHBC is possible when there is an adequate means of transport. However, transportation for most home based caregivers and the client remains a major problem, especially to those who are living in the rural areas where the roads are poor (Odek & Odo, 2007). It has been documented that those undertaking voluntary home based care

responsibilities, sometimes have to walk long distances under the hot sun to arrive at their patients (Cunningham, *et al*, 2007; Campell *et al*, 2005).

Mohammed & Gikonyo (2005) stated that in many programs lack of resources, such as transport of the personnel and client, could be due to inadequate funds. For many community based health care workers, the success of the program requires that the organization have their own vehicles or are subsidized so that they can possess their own transport and also receive transport allowance (Friedman, 2002). A study conducted in Kenya, has shown that volunteers are not paid for their time, but the organization provides some volunteers with training and allowances to cover necessary transportation (Thurman, Hoffman, Chatterrji & Brown, 2007).

2.4 CONCLUSION

Home and community based care is not the only solution in addressing the AIDS epidemic in Southern Africa, but it has been shown to be the best strategy for increasing the quality of care for people living with HIV/AIDS. It is important that efforts by the government, private sector and non-governmental organizations should collaborate with one another to deliver effective care. The challenge of caring and supporting PLHAs is overwhelming. Challenges such as support, training of the caregivers, financial difficulties and voluntary activity should be taken into consideration in the planning phase of home based care program.

Home based carers should receive proper recognition of their work, experience, knowledge and individual needs since lack of recognition to their services can affect different carers in different ways. CHBC can be effective and affordable when there are good results in the health and social status of the patients, families and community as a whole. Many of the challenges and limitations do not only affect the ability of caregivers to carry out their activities, but can aggravate condition of poverty and gender inequalities.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 INTRODUCTION

The purpose of this chapter is to focus on the qualitative research methodology utilized in the study. A description of the research design, the research setting and context will be provided. The methods of data collection and methods of data analysis are described.

3.2 RESEARCH DESIGN

A qualitative research approach, with a case study design, was chosen to understand human actions and ‘behaviors best understood within their natural setting as opposed to the somewhat artificial settings of experiments and surveys’ (Babbie & Mouton 2001:270). Case studies research is appropriate when investigators desire to investigate the research topic broadly in order to retain the holistic and meaningful characteristics of real life events (Burns, 2000). The Umtha Welanga Community Organization (UWCO) constitutes the case, with an in-depth exploration of challenges they encounter as an organization when providing home based care services. “Case studies provide an in-depth description that represents an understanding of actions and events and is described as an intensive investigation of a single unit varying from individual people, families, communities, social groups, organizations, institutions, events and countries” (Babbie & Mouton, 2006:271).

Qualitative research was chosen as “the research occurs in the natural setting, focus on process rather than outcomes, insider’s perspective is emphasized, primary aim is in depth and understanding of actions and events and to understand social actions in terms of its specific context rather than attempting to generalize some theoretical population” (Babbie & Mouton 2001:270). One of the unique features of a qualitative research methodology is the small number of participants which translates into in-depth questioning and richness of data which cannot compare with quantitative data (Slauenwhite & Simpson, 1998). Many

sociological studies are often based on small samples drawn from one local area, but although these samples may attempt to be representative of a specific category of people, they are not probability samples from which the results can be generalized to the whole population (Arber, 2001).

3.3 RESEARCH SETTING AND CONTEXT

The research took place at the Umtha Welanga Community Organization (UWCO) in Khayelitsha, South Africa. The township has three Provincial government clinics and the majority of residents depend on health services provided by the government. The community is characterized by a high rate of unemployment (Coetzee, Hildebrand, Boulle, Maartens, Lous, Labatala, Reuter, Ntwana & Goernaere, 2004).

The Umtha Welanga Organization (meaning rise and shine), is a community based project in Khayelitsha founded in the year 2000. It helps communities cope with and take care of the increasing number of families and children infected and affected by HIV/AIDS. The organization seeks to provide a loving and supportive link between terminally ill parents and the future caregivers of their children, as well as facilitating a relationship between the biological parent and the intended foster parent. The target groups are orphans, vulnerable children and families in crisis because of HIV/AIDS. The organization also works with foster or extended families through a support network providing screening, training, counseling and monitoring of children in alternative care.

The support services focus on support group and counseling, family and life skills training, information and training about positive living, nutrition and parenting skills, referrals, follow-ups and links to a hospice and also assist with state grants. In the foster care program they train staff, foster parents, support groups and volunteers. These families are supported by regular home visits from qualified child care workers and social workers who help with legal placement processes and state childcare grants. Lastly, the income generation skills program is responsible for food gardens, crop production, beadwork, and crafts.

The home based care program was implemented in January 2008 after having realized that those suffering from HIV/AIDS are being neglected and not cared for. The organization recruits its home based staff from people who are residents of the community of Khayelitsha. The criteria to qualify to become home based care workers are those that are currently unemployed, those who have previously done volunteer work, have the ability to demonstrate empathy with the client, are able to cope in stressful situations, commitment to the community, good communication skills, have received training on care, support, and counseling, and have the appropriate level of literacy. The organization has employed five full time home based care workers and two volunteers based on the above stated criteria.

The goals of home based care (HBC) are to work with terminally HIV/AIDS clients and to ensure that they are not defaulting and are clean. The UWCO's mission is to make the HIV client stand up, take the treatment and make sure that they are physically clean. The UWCO gets its clients from the clinic so that they can give them counselling. Home based carers support the client at home and also make an assessment whether they have suitable family members to support them, and if not, refer the client to the hospice in consultation with the organization management and health personnel such as the social worker. The services of home based care are provision of counselling, basic nursing care to the client such as feeding, bathing and giving medication, assistance with housework, help families to receive cash allowances for food and school uniforms. They ensure that the basic needs of people living with HIV/AIDS are met. Home based carers provide food parcels, establishing support groups and promoting information sharing, addressing needs of child headed households and provide palliative care.

3.4 THE POPULATION

The population is defined as “a complete set of individuals or items that a researcher wishes to study in a particular category” (Hinton, 2004:48). The population used in this study consisted of all the employees of the UWCO such as the general manager and six home based care workers. The study was limited to one community organization and its findings may not necessarily apply to all home based care organizations.

3.5 DATA COLLECTION

3.5.1 Research instrument

The unstructured interview schedule was designed and based on the study objectives and informed by the literature review. Questions were formulated in simple words. The interview schedule was administered during the in-depth interviews to collect data from the study participants. Observation that provides insight into the workings and dealings of the participants was also carried out. Field notes were taken to account for what the researcher heard, saw and experienced.

The main instrument used to collect data was an interview schedule and also the questionnaire comprising of five demographic- and fifteen open ended questions. Two interview schedules were developed, one for management and one for the home based care workers. The interview schedule was divided into two sections. Section A consists of questions relating to demographic data such as age, marital status, educational status, religion and employment. Questionnaires were also developed to obtain a general view of the participants' demographic characteristics. In section B, questions were open ended, covering aspects relating to home based carers' training received, their duration with the organization and conducting home based care, support system from the organization, challenges experienced (financial, physical, emotional stress), benefits, attitude of the management and their concerns and worries of being home based care workers. Section B of the interview was recorded using a tape recorder.

The interview schedule for management also consisted of two sections, section A relating to demographic and section B consisting of twenty eight open ended questions. These included aspects such as goals and objectives of the organization, services provided, management structures, support from the government, community and other institutions, financial challenges of the organization, volunteering from the community and supervision were investigated. The interview lasted approximately one hour and was recorded with a digital recorder and transferred to a compatible disc. The interview was transcribed immediately after completion of the data collection.

3.5.2 Administration of instrument

In-depth interviews were held at the offices of UWCO in the Masiphulisane community centre at Khayelitsha. Permission was granted by the coordinator of the organization and the home based caregivers.

The respondents signed the consent to be tape recorded. The permission to tape record the interview was requested before gaining entry to ensure that there was transparency, negotiation, interest, disclosure and mutual trust (Neuman, 2000).

The purpose of the research was explained to the participants before commencing with the interview and participation was voluntary.

3.5.3 Collection of Data

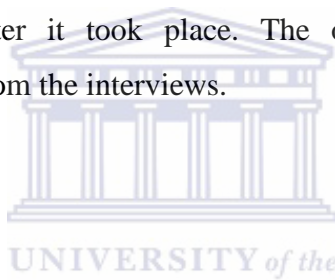
Data was collected during September 2009 at UWCO offices in Masiphulisane Centre in Khayelitsha. The researcher was the primary instrument of data collection. Before conducting the interviews, permission was requested from the management and home based care givers. In addition to the verbal agreement made, an informed consent form which explained the purpose of the study, nature of the research and responsibilities of the investigator was signed. Neuman (2005:527) states that “if social researchers are involving human beings as subjects in research, it is required that subjects legally authorize or sign the informed consent form for protection and ensure that legal steps are followed”.

The researcher established rapport with the respondents with an aim of understanding and also to see situation from their viewpoint (Denzin & Lincoln, 2000). The respondents were all the employees directly or indirectly involved with the community organization. An appointment with the caregivers was scheduled and a suitable venue (UWCO empty office) was used to conduct the interviews. All interviews were conducted after informed consent was obtained from the interviewees. As Babbie & Mouton (2006: 522) state that social research should never cause any harm to the participants regardless of whether they volunteer for the study or not, the researcher was very careful in the kind of question asked

not to cause any harm. The researcher had to constantly probe to encourage respondents to talk more and any verbal gestures before and after the interview were observed and recorded. The venue had comfortable chairs, was free from disruption because employees were notified not to disturb the respondents and therefore ensuring maximum privacy.

Observation was also employed to describe the setting, activities that took place in that setting, people who participated in the study and the meanings that were observed from the perspective of those observed (Patton, 1990). According to Babbie & Mouton (2006) observation has great advantages such that the researcher is present observing and thinking on the scene of the action. Another advantage of being a participant observer was to discover aspects that no one else has really paid attention to. Field notes were taken to account for what the researcher heard, saw and experienced. The interviews were transcribed immediately after it took place. The observation served to verify and complement data obtained from the interviews.

3.6 DATA ANALYSIS



Data analysis started with the transcription of the information from the audio tape recordings. Interviews were transcribed verbatim. The transcripts were read thoroughly several times, making as many headings necessary to discuss all aspects of the content. The broader categories were sorted into clusters and categories and from this, the themes emerged and the researcher was able to investigate relationships between them. Thematic analysis was employed to analyze or make sense of the data gathered through observation and audio tape techniques derived from the interview with the home based caregivers and management of UWCO. Thematic Analysis is a method for identifying, analyzing and reporting patterns (themes) within the data (Braun & Clarke, 2006). Furthermore, a theme captures something important on the data in relation to the research question and represents some level of patterned responses or meaning within the data set. Coding of the data assisted the researcher in gaining relevant data that was used to address the aim of this study, also to minimize a lot of raw data into manageable quantity, making it easy for the researcher to access relevant data (Neuman, 2000). Coding refers to the creation of

categories in relation to data; the grouping together of different instances of datum under an umbrella term that can enable them to be regarded as ‘of the same type’ (Braun & Clarke, 2006).

Transcripts were reviewed to compare interpretations of the research findings. After transcription, the researcher cleaned the data to ensure that data is useful and functional toward the intended end analysis (Babbie & Mouton, 2006).

3.6.1 Trustworthiness

Trustworthiness is an essential component of qualitative research and is measured by credibility, which is determined by the match between constructed realities of the respondents and the reality presented by the investigator (Lincoln & Guba, 1995). Trustworthiness in this study was undertaken through member checks (Lincoln & Guba, 1985) in which the answers given by staff and home based care givers of the organization were evaluated to assess the intentionality of respondents, correct the obvious error and to provide additional volunteer information (Babbie & Mouton, 2006). Firstly, the researcher returned to the participants to check that their responses were well interpreted and thus minimizing bias from the researcher. Secondly, audio tape was double checked by replaying it over again to confirm if the data entered was genuine.

3.7 LIMITATIONS

The study was conducted with one community based organization in Khayelitsha. Findings are only applicable to this organization and can therefore not be generalized to all community based organizations providing home based care.

3.8 ETHICAL CONSIDERATIONS

Ethical guidelines serve as standards and a basis upon which each researcher ought to evaluate her/his conduct (De Vos, Strydom, Fouche, & Delport, 2005). Participants gave their consent to participate. They were briefed before the interview explaining the goal,

procedure and advantages of the study. They were informed that participation in the study was voluntary and that they may decline to participate without penalty. Participants would have the opportunity to withdraw at any stage of the interview. Participants were informed about the risks and benefits of the study. Confidentiality was guaranteed with regard to private and personal information. The data collected was kept confidential. To protect the respondents from possible negative effects of their responses, the names of the management of the organization and of the respondents were withheld in the final report.

3.9 CONCLUSION

This chapter presented a discussion of and reflection on the research methodology and covered the qualitative approach, the research process, data collection, data analysis and ethical considerations of this research project. The qualitative findings will be discussed in Chapter 4.

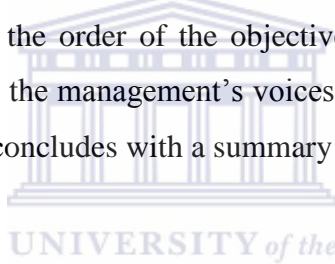


CHAPTER 4

RESULTS AND DISCUSSION

4.1 INTRODUCTION

This chapter presents the results of the research and discusses the data obtained through face-to-face interviews with home based carers and the management of Umtha Welanga Community Organization. The overall purpose of the study was to explore the challenges faced by UWCO in the provision of HIV/AIDS home based care. The objectives of the study were firstly to examine home based care provision of UWCO, and secondly, to explore the challenges faced by UWCO in the provision of HIV/AIDS home based care. The results are presented in the order of the objectives of the research. Throughout the data, the participants' voices, the management's voices and the researcher's interpretations are interwoven. The chapter concludes with a summary of the key findings.



4.2 DEMOGRAPHIC CHARACTERISTICS OF CAREGIVERS

Prior to the interviews, home based caregiver participants completed a questionnaire to collect their social demographic characteristics. The demographic details revealed that all the participants were black females living in the township of Khayelitsha. The participants' home language was reported as IsiXhosa.

4.2.1 Age

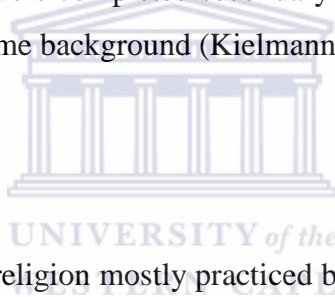
The age of home based caregivers ranges between 20 and 40 years. A study conducted in Thembaletu Home Based Care, Mpumalanga demonstrated that the mean age of caregivers was 39 years old (Zerden & Billingham, 2006), which is consistent with the results of the current study.

4.2.2 Marital Status

Fifty percent of the respondents were married and the rest were all unmarried living with their relatives.

4.2.3 Educational Status

In relation to education, all six home based caregivers attended government schools and have completed Grade 12, which is the reason of having lower skill. A few of the home based caregivers advanced to the tertiary level. A study conducted in Tanzania confirmed that most of the HIV home based caregivers had received limited education and were not formally employed (Pallangyo & Mayers, 2009). Another study in Zambia documented that most home based caregivers completed secondary school and very few were formally employed and from low income background (Kielmann, Cataldo & Musheke, 2010).



4.2.4 Religion

Christianity is the dominant religion mostly practiced by home based caregivers. Religious faith is a powerful source of comfort to caregivers living in Uganda and South Africa such as reading the Bible every morning before engaging in care work (UNAIDS, 2000). Furthermore, involvement in religious customs and activities such as praying, faith and belief in God helps caregivers to cope with stress and burden of care giving (Adams -Tufts, Wessell & Kearney, 2010). In Botswana, some caregivers also had found religion to be a source of comfort, and also helped them relieve stress, retain a sense of control and maintain their sense of meaning and purpose (WHO, 2005).

The above section presented the socio-demographic profile of the respondents.

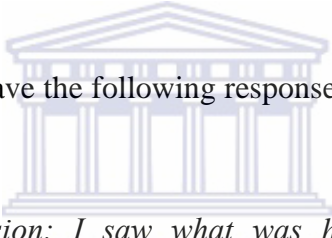
4.3 THE UMTHA WELANGA COMMUNITY ORGANIZATION

This section focuses on the establishment of Umtha Welanga Community Organization (UWCO) with regard to home based care.

4.3.1 Establishment and purpose of UWCO

The coordinator and founder member of UWCO, who resides in Khayelitsha, had a vision of helping community members who were sick due to HIV/AIDS. This was after witnessing the negative treatment from their families and community with regard to HIV/AIDS clients. People who were diagnosed with the disease were rejected and received no support from their families and community. In the year 2000, she enrolled for an HIV/AIDS course to gain more knowledge and understanding on care and support for people infected and affected by the disease. Her desire to start the organization was further motivated by the passing of a family member as a result of HIV/AIDS which led to the establishment of UWCO in April 2001.

The coordinator of UWCO gave the following response on why and when the organization was established:



“Actually I had a vision; I saw what was happening in the community especially in HIV/AIDS. The people who were diagnosed with the disease were being rejected and there was no support by the community and their families. Anyway, I don’t blame them because they did not have the information about the HIV. In the year 2000, I started to have the vision to do something about this problem and then enrolled for the course on HIV. Eventually, it hits one of the family members, my sister”. (Coordinator)

People are driven by different reasons and ambitions to establish care organization. It was therefore important to find out what the aim of the organization was. When asked what the aim of an organization was, she responded that:

The aim of UWCO is to help communities cope with and take care of the increasing numbers of families and children infected and affected by HIV/AIDS. The organization seeks to provide a loving and supportive link between terminally ill parents and the future guardian of their children, facilitating a relationship between the biological parent and the intended foster parent. The target group is orphans, vulnerable children and families in crisis due to HIV/AIDS. The organization works with foster or extended families

through a support network providing screening, training, counseling and monitoring of children in alternative care.

The main focus of this organization is to receive people from the clinic who are diagnosed with the disease to attend support groups and give them one on one counseling. There was also a need to work hand in hand with the family members of those infected to give them information about HIV so that they are equipped to conduct basic nursing care to their family members such as feeding, bathing and administration of medication. The reason for opening the extended family and foster parent network was to build alliances and friendships between the family and community (Coordinator).

It can be concluded that UWCO was established after the realization of a need in the community. The aim of establishing UWCO was to help communities cope and take care of the increasing numbers of families and children infected and affected by HIV/AIDS.

4.3.2 Establishment and duration of care services

In January 2008, the home based care services program was introduced at Umtha Welanga Community Organization. HBC supports the client at home and also makes an assessment together with the social worker of the living conditions such as housing, number of people in the house, breadwinner and the dependents. This is followed by a referral to the hospice if the client qualifies to be placed in an institution.

When the question about length of service at UWCO was posed to the caregivers, the following responses were given:

“I started in 2008, November, which is about 10 months now, 2008 last year, and if I count properly, it is 10 months”. (Home Carer 1)

“Okay, I started to work at UWCO in May 2009. It is about four months now”. (Home Carer 2)

“I think it is one month because I started in August”. (Home Carer 3)

It can thus be concluded that the period of service by the home based caregivers at Umtha Welanga Community Organization ranged from one to ten months during the period of

interview due to the fact that the HBC service was only introduced in 2008. It is crucial that caregivers are provided with sufficient and regular training on quality home-based care and support.

4.3.3 Education and Training

The UWCO does not offer any formal training to its staff except workshops conducted by the Department of Health and Social Development. Some of the home based caregivers are hired as qualified carers who received their training from the Department of Health. Home based caregivers have to complete a home-based care course facilitated by the Department of Health as well as continuous in-service training to ensure competence (Department of Health, 2001). Moreover, community-based training of home-carers is based on adult education principles and simple practical guidelines. The training enables them to recognize and support the health needs of the people they care for and administer medication or refer them if necessary so that people living with HIV have access to the medications that they need.

It was established that some of the UWCO staff members who conduct HBC have found it easier to execute care work such as administering of medication, feeding, bathing the clients and mouth care, due to the interaction they had with the client and those caregivers who have received training. Through this interaction, they develop the necessary skills which are a requirement to render their services in their community. Some of the skills being utilized in caring are acquired informally such as accompanying a fellow home base caregiver on home visits. However, staff upgrade of skills is done through in-service training.

The coordinator gave the following response when asked about the type of training which is given to the home based carer:

“Actually we are not giving training for the home based carer. But we only develop necessary skills which are a requirement to their services. The home based carer does their training with other institution such as the Department of Health, in other words they come to us as qualified carers. But for us we also develop them with more skills that they require.

We have got the fund whereby we send them to any kind training that we feel there is a need to receive. This is not only done for the home based carers but also this applies to the community workers and social workers” (Coordinator)

However, she points that training equips home based carers to:

“Training empowers home based caregivers to deliver their services professionally and skillfully without any judgment to their clients. They become knowledgeable about methods that are used to take care of people who are terminally ill which exposes them to nursing experiences. Training helps individuals and families deal with HIV prejudice and promote an informed understanding of living positively with HIV/AIDS. Caregivers learn to provide loving supportive links for terminally ill parents of children diagnosed of HIV”. (Coordinator)

Hence, the home based care giver responded in the following manner when asked if there is any training received before working with UWCO:

“Yes, I did receive home based care training for three months in Mitchell’s Plain. It was a school. I then went to Kraaifontein to do practical for about three months in an old age home. After then I was called to start working at UWCO. I was trained to look after sick people and children with different diseases such as cancer, diabetic, people who have epilepsy and also HIV/AIDS, help people who need the first aid. Modules which were offered includes: role of caregivers, basic information on HIV/STD and TB, communication skills, spiritual and cultural issues, infection control, principle of palliative care and basic nursing care, nutrition”. (Home Carer 4)

Another caregiver acknowledged that the organization does offer some workshops, however she pointed out that she has not yet attended any training through the organization:

“The organization does offer some workshops, but since working in this organization, I never attended any”. (Home Carer 6)

Evidence has shown that education and training empowers caregivers to conduct their service professionally and competently. As a result, they become equipped with knowledge and skills to render nursing care services such as bathing, feeding and giving medication to

the client. Moreover, they are empowered to counsel those with suicidal thoughts and also not to be judgmental when they render services to clients. A home carer at UWCO supported this notion or use of a similar word:

“The training helps us a lot because other people you find that they are devastated and in hopeless situation. Others wish to commit suicide. After you receive the HIV/AIDS training, you are able to give them hope and you are able to handle sick people by bathing and feeding them. After you give them counseling, they are able to rise up and live again. Unlike people who didn’t receive training who will just help people without the knowledge and skills of rendering care services. Training empowers us to do our service professionally, skillfully and effectively without judging them. It also assists us to have good communication skills and interact with them, after receiving training you know what you are talking about. It also helps us how to wash bedridden patients, feed them and give medication or treatment. You are able to do home based care service competitively because of training that you receive”. (Home Carer 3)

The seventy volunteers who attended training in Entabeni, KwaZulu-Natal which was led by a qualified sister/nurse, reported that the training has added the sense of personal motivation, confidence and credibility (Campell, Nair & Maimane, 2007). Furthermore, the training had increased respect and level of recognition to their work which was shown by the community members and traditional leaders. UNAIDS (2008) affirms this by stating that ongoing training provides staff members with skills and knowledge necessary to be able to fulfil their roles as carers and to cope with the environment in which they work.

It can therefore be concluded that UWCO does not offer any formal training to caregivers but a few of their staff members are trained by other institutions such as the Department of Health to ensure competent skills. The HBC team has also indicated that by attending the training courses or sessions, they are competent in taking care of the terminally ill client, able to give people hope, helping to bath and feed clients and also to administer medication and treatment.

4.3.4 Benefits of care giving services

There are many benefits in conducting training. The training empowered the carers with a sense of personal motivation and confidence. It also gives them respect in the community.

When asked about the benefits of working at UWCO they responded:

“The benefits of doing home based care is that you accumulate lot of experiences when working with this organization because you don’t only learn about home based care programme but you also become more knowledgeable with other services. Example, you are also equipped with other skills such as child headed households. The other benefit is that you experience satisfaction after assisting someone who is sick and helpless. You experience joy and fulfillment inside your heart“. (Home Carer 3)

“Do you know what,I think there are benefits. For instance, if in the township the parents died because of HIV, I’m able to advice children to go to UWCO for the food parcel“. (Home carer 4)

Working with this organization is helping me a lot because I’m getting more experience and if there is someone sick in the family or neighbor, I can be able to help that person”. (Home carer 6)

Training empowers caregivers and provides them with different skills and knowledge through programmes such as income generating skills, home based care and community work. Furthermore, training equips them with knowledge and counseling skills so that they can help people who are in desperate situations and are unable to accept their HIV status. Counseling prevents clients from committing suicide and assists them to accept their status.

“I was engaged in programs such as women wellness, to talk about women in the community and also community based life skill. Some people didn’t know about the contraceptives, they used to think that if you use contraceptive you cannot give birth again. And I will also visit the child headed household to find out if they have food, uniform and they are well. There are many benefits of working in UWCO. We learn about all the programs offered in the organization. You get empowered with different skills such as communication skills, writing skills because you need to write a report every time you are from home visit”. (Home Carer 1)

“I’m doing two programs which are foster parents and HIV/AIDS. I love doing this job. In foster parent’s programs, we are dealing with parents that are taking care of their grandchildren. We also do support group, in support group they offload their situations, maybe they are experiencing problem with their grandchildren so that we can give them advice in order to meet halfway. You are expected to know all this programs so that when someone ask you what is UWCO and must be able to explain to that person. I’m also the facilitator of the foster parent program”. (Home Carer 2)

It can be concluded that home based caregivers received vast and broad experiences regarding care services from other organizations before being employed by UWCO. In the next theme, support system from the family, community, organizations, institutions, schools, churches and health care sector will be discussed.

4.3.5 Support Systems

Caregivers vocalized that they receive good support from the organization through the coordinator and supervisors (which are social workers). Caregivers are encouraged to be transparent when sharing problems with the social workers. Both the caregivers and supervisors resolve problems as a team. The following emerged:

“Yes they do give me support in the organization because if do have the problem out there, I approach the social worker who is my supervisor. If the social worker cannot help me, I approach the coordinator. There are lots of problem out there, if I have a challenge I do explain to the coordinator or social worker and then they solve that problem. Like there are times when the clients don’t have transport for people who want to be referred to the hospice, it is then that the organization has to make a plan. But sometimes the client does have their own transport. There are other times when you find that the client does not have the money to go to the hospital because he/she is not yet receiving grant. You need to assess first the state of the family before the organization can assist. We also distribute food parcels to the orphans”. (Home Carer 4)

“To be honest, they do give us a lot of support. For example, in the community sometimes you find that the client is having some problem and difficulties. You raise that problem to the supervisor or social worker and will listen to us. Then the organization will intervene by offering help to

that particular person if they could ... We are still in the process, but I wants to say that they really give a lot of support”. (Home Carer 5)

When experiencing any emotional and psychological trauma, they are given moral support by the social workers and supervisors to be strong, and they are encouraged to speak up since their work is very demanding. Another caregiver reported that:

“Yes, the organization does really give a lot of support. For instance, sometimes you experience depression and anxiety due to the kind of work you are doing. The social worker and my supervisor when I suffer from emotional and psychological experiences, they do help by encouraging me that I need to be strong since this kind of work is demanding. The other thing is that when you face any problem in the home visits, they advice us that we must speak up, so that the organization can do help. It is sometimes painful to see orphan children on their own, no parent to guide them. This does affect me a lot. However, thanks to UWCO management for being understanding and supportive to the care workers”. (Home Carer 1)

Some of the difficult families who are frustrated by care work even offend home based caregivers. Supervisors accompanied caregivers to persuade the family members and clients in being loyal and sympathetic to the home based care workers. This is demonstrated by the following:

“They do help us a lot because when you do home visit there are many problems that we encounter. Example, Other families or people will start to insult; they will question you on who told there is a sick person in this family. As a carer, you need to explain properly to them that you are doing door to door visit to explain or empower people about HIV/AIDS and nobody who has informed you that there is an HIV client. It is very difficult. Otherwise in the organization they do help us a lot and encourage us to be tolerant and understanding”. (Home Carer 6)

Most carers have shown that they are given huge support from the organization, particularly from the coordinator, administrator and the supervisor (social worker). UWCO links with various organizations around and outside the township, and formed a network. Networking includes close coordination and collaboration with other organizations that provide complementary care such as hospitals, clinics, hospices, schools, home- and community-care programs, government and international partner programs in other sectors,

community groups, legal services, and home, PLWHA support groups, orphans and vulnerable children programs and advocacy organizations.

Since HIV/AIDS epidemic poses challenges such as emotional exhaustion, anxiety, and depression to both caregivers and the client, it is necessary that they are given a holistic support to address their physical, psychological, spiritual and social needs in order to maximize efficiency and effectiveness of service delivery. These quotes further support the above argument:

“My coordinator and supervisors supports me a lot, even though sometimes there are misunderstandings and differences between the management and caregivers because as human beings one cannot be happy all the times”. (Home Carer 2)

However, some home based caregivers in some instances experience rejection from the client and lack of support by household members. They felt that they are not given support by the client. The following citation supports the comment:

“The client will refuse to be helped because the one she knows didn’t come. She will tell you that I will only bath when that one comes. So it is a challenge really. You really need to be down until the client agrees. Sometimes you are not welcomed and they will ask you many questions such: Who said we have got a sick person in this house? Who said we need your help? They can even shut the door in some instances to show that you are not welcome” (Home carer 5).

Moreover, in other households some relatives turn to exploit and ill treat caregivers by expecting them to perform all the household chores and render care services. The perceptions of some relatives are that caregivers are paid by the government to perform care work services. This quotation demonstrates the above statement:

“There are those families whereby because there is a caregiver who normally comes to render care services, they turn to relax. They will not help to wash the client but will only wait for the care giver to bath him. As carer, our responsibilities are to assist or meet half way with the family and not to take over caring for the client. They will take advantage of us because they think we get paid for such services. We are only there to assist”. (Home Carer 6)

Community and home based care cannot be accomplished by one sector in the society; it requires the support from other sectors such as Department of Education, Social Development, Local Government, traditional leaders, faith based organizations, non-governmental organizations and community organizations (National Department of Health, 2001).

Mohammad & Gikonyo (2005) also argue that community home based care programs cannot be successful unless they receive active support and full involvement from the government, NGO's & communities. The National Department of Health (2002), states that when organizations co-operate with each other, weakness of one sector in a specific area can be complemented by the strength of another. An organization can therefore improve their service delivery through learning from the expertise and experience of others. Therefore, an integrated approach has the potential to respond to the needs of the infected and affected (SAFAIDS, 2008).

The coordinator of UWCO confirmed the importance of collaboration or use of multi-sectoral approach as an effective method in home based care by stating:

“We also felt that that there is a need also to work hand in hand with the family members to give them information about HIV so that they are empowered, it was the reason we opened extended family and foster parent network in order to build alliances, friendships with the family and community. We will only work with the families after the clients have disclosed their status to the family. There are lots of organizations that we link with most of the organization around the area and outside the area. We formed network with them. Yes, we do network with other organizations and structures such as churches, schools, hospices, government, government Department such as child welfare, health and social development. We do form relationships with the local welfare department, schools, churches businesses, hospitals and clinics. As an organization we do not only do the home visit but we do school visit in order to monitor the progress of the child academically, doing psychosocial support for the children in order to identify how they are coping socially and psychosocially. The school teacher will then give us the information on child development since he/she is the one working closely with the child. And also we have the school holiday program“. (Coordinator)

The organization forms relationships with families, schools, organizations, churches, the hospice, private sector and government departments to work in collaboration. They create a network with other institutions to work effectively. The possibility of home based care service delivery is guaranteed when all the sectors are involved and are working in partnership.

4.3.6 Monitoring and supervision

Monitoring of a CHBC programme involves supervision (usually by a nurse) to ensure adequate and effective care delivery, which might mean monitoring care activities such as conducting site visits to assess care and promoting peer supervision. Furthermore, access to essential drugs, supplies and equipment must be monitored and adequate staffing and continuing CHBC education must be provided (WHO, 2002).

The supervision includes providing support in solving problems, training to help improve performance, review individual performance. All information are recorded after the visit to ensure proper follow up, coordinators and professionals (social workers) meet once a month to discuss relevant cases, issues, problems and ways to improve the programme (UNAIDS, 2001). The responsibility of social workers in the care programs is to make counseling visits to the caregivers for psychological empowerment and assess their socioeconomic conditions for possible help intervention; facilitate the process of positive change of attitudes and norms relating to care giving among the caregivers; and therefore give way to increased care-giving productivity (Kang'ethe, 2009).

UWCO works in conjunction with the social workers of the Western Cape. The organization is responsible for doing assessments of the living condition of the client, orphaned children if they have food, school uniform and other basic needs. The social worker collaborates with other professionals such as nurses; volunteers to enhance all aspects of client care (De Silva & Clark, 2005)???. The home based carers meet the social

worker every Friday where they report or give feedback regarding their experiences during home visits with the client and their families during the week. The supervisor accompanies them at least twice a month while they conduct home visits. Supervisors build mutual relationships between caregivers and their clients together with the families. This was emphasized by the following comments:

“The social worker and supervisor do accompany us to the family if the client is refusing to be helped. They will try to explain to the client that as home based care, we help people who are terminally ill and needs assistance. After long persuasion, it is then that the client will accept the help and disclose the status”. (Home Carer 5)

“The home based carers meet with the social worker on every Friday on a weekly basis. They give report or feedback to the social worker every Friday whereby they discuss their experiences during home visit with the client and families. The supervisor will at least accompany them twice months when they do home visit”. (Coordinator)

Supervision ensures that all aspects of service delivery are addressed and home based caregivers needs are met (National Department of Health, 2007). Therefore, it is vital that the home based care program is monitored and supervised to ensure that caregivers are supported, mentored, nurtured, motivated, counseled and guided in order to build trusting relationship with the subordinates.

4.4 CHALLENGES EXPERIENCED WHEN PROVIDING HOME BASED CARE

4.4.1 Gender equality

Gender imbalance in people providing home base care services is reflected by the all-female component of home based carers of the UWCO organization. All the employed home based caregivers of UWCO are female, with two to three males who are involved in managerial positions. The coordinator confirmed this statistic:

“Actually, most of our staff operating in this organization is female. The same with the client, it is the females who normally disclosed their status.

We do have few men who are helping. You find that they are two or three. We have just started a program called gender health specifically focusing on the father to do HIV awareness campaign. We do door to door visit to ensure that men are involved in great numbers because the HIV/AIDS does not only concern women but affect us all regardless of whether you are male or female”. (Coordinator)

Traditional gender norms result in more women and girls providing care and it also creates social barriers to men and boys becoming care givers (UNAIDS, 2008). It has been demonstrated that the work of caring for people who have HIV/AIDS is primarily the responsibility of women and girls (Ogden, *et al* 2004). However, UWCO has introduced a new program aiming to promote men participating in care services and a HIV awareness campaign called gender health. In this program, men are engaged in a door to door visit campaign. This will hopefully lead to an increase in the number of men becoming involved in care work.

It can be concluded that women are the primary caregivers and spend active days and nights providing care to ill relatives, coupled with their general domestic chores (Opiyo, Yamaano & Jayne, 2008). The following quote from Mr Nelson Mandela reiterates the above “Women don’t only bear the burden of HIV infection, they also bear the burden of HIV care, and grandmothers are looking after their children. Women are caring for their dying husbands. Children are looking after dying parents and surviving siblings” (Nelson Mandela, 46664 HIV/AIDS Awareness Concert, 2005).

4.4.2 Finance

The entire staff of UWCO including home based caregivers agreed that finance is the greatest challenge faced by the organization. Lack of funding makes the operation of an organization difficult. The management acknowledges that the funding from the Department of Social Development, Ashford Rotary Club, Newlands Rotary Club, HOPE HIV, Stephen Lewis Foundation, Engender Health and HEVA assist in paying staff workers and the smooth operation of the organization. However, they pointed out that it is still not sufficient to cover all the costs and expenses of the organization. They

continuously apply for funding to different institutions and in most cases are turned down. The coordinator reiterated this challenge:

“Actually, finance is the greatest challenge that we experiences. Actually it is the biggest challenge to any organization, and those who can say we don’t have the challenge I can say they are very lucky. But you have got to work very hard on that one. We keep on applying almost all the time, some gives us regrets. The solution is to keep on knocking until someone opens the door” (Coordinator).

Poverty and a high rate of unemployment were found to be the driving force behind women’s involvement in home based care. Most care workers felt that if offered better salaries elsewhere, they would quit this job. Caregivers expressed dissatisfaction regarding the kind of payment offered and complained that it is insufficient to meet their basic needs. Their response is documented as:

“The most challenging issue is only money or the salary. The salary is not sufficient to meet our basic needs but can only help you to survive” (Home Carer 2)

“The salary we are paid is R1000, 00 per month for home based care. The money that we receive is not sufficient to meet the basic demands. Yes, generally I love the job which I am doing, because I like helping people but the most challenging issue is money because I cannot be able to meet all the demands and sustain myself. I can only be able to help me buy soap, some food but it is not enough. The money is not enough to make me happy but at least the organization does give us some money for the transport. Otherwise, I love doing this job since I like helping people who are helpless. The amount of money is not enough. For the time being I will be working for UWCO until I find a better job with good salary” (Home Carer 3)

“There is no money in this kind of job. Otherwise, I console myself by saying that things will become better one day. The other reason is that you have volunteered by yourself to offer care services without anyone forces you. Finance is a big problem when you are doing this kind of job.” (Home Carer 5)

The salaries paid to home based caregivers vary from organization to organization, hospice to hospice and is therefore not uniform (Department of National Health, 2002). The

minimal salary received by care givers forced them to look for better opportunities in order to sustain themselves and their families financially (Department of National Health, 2002). Sometimes families of home based caregivers become resentful because they work hard for no money. In some instances their partners have walked out or they had to leave the volunteer home based care work because of the lack of support from families (UNAIDS, 2000).

It can be concluded that finance is the biggest obstacle in the delivery of services by home based caregivers. It has also been indicated that the organization needs more funds to run and operate effectively. Unfortunately, their application for funding is sometimes turned down by other finance institutions. If home based care programs are to be sustainable in playing a vital role of caring and support of people with AIDS, proper remuneration arrangements and support structures must be put in place (Campell, *et al* (2008). In a study conducted in Zimbabwe, it has been highlighted that a stable economic environment is a key pre-requisite for the successful running of HBC projects because when funding agencies delay the release of funds, project costs and budgets are affected (SAFAIDS, 2008). In a poor resource setting where finance is a dilemma to sustain and pay workers, it is important to promote the use of voluntary service by community members.

4.4.3 Voluntary services

Volunteering service is a two way process benefitting not only the organization but also the community. It benefits the entire community because people gain skills and experiences with regard to home based care. Majority of the caregivers agreed that they were not forced by any situation but they voluntarily opted to become carers. When they were asked if they voluntarily chose to become home based caregivers or were forced by circumstances, they responded:

“I volunteered to do home base care work and was not forced by anyone as I told you that I’m social worker who did not go to school. My desire is to help individuals who are vulnerable as results of HIV sickness, either orphan children or individuals who are terminally ill”. (Home Carer 1)

Others revealed that they saw a need to contribute toward their communities to assist those infected and affected by the disease. They articulated that service rendered is driven by passion and love for the people.

“Yes, I’m not forced by any circumstance, but I love this job. My father was sick and he had stroke, that’s how I became interested in community work to help people, because while he was still alive, I was helping to bath him. That’s when the passion of helping people started to develop”.
(Home Carer 2)

“You know, if you are a carer you must not put money first but should be there to serve. You need to forget about yourself first in order to help such people. If you don’t have the heart for serving people, you cannot enjoy doing this work. It must be something that you love to do and not forced”.
(Home Carer 4)

While most of the participants vocalized that their dream was to become a professional nurse or social worker, unfortunately they never got an opportunity to fulfill their dream due to lack of finances or poor matrix results. Most of the caregivers indicated that the reasons for their involvement in HIV/AIDS care services came firstly, as the result of life changing experiences from members of their family/community or close relatives who are infected by the pandemic. Secondly, others are driven by passion to care for the sick and helpless clients in the community such as those staying alone and without family members to assist them. When asked if they voluntarily chose to perform home based care or were forced by circumstance, the following reply was given:

“I volunteered myself to do home based care. I was never forced by anyone. I have chosen Home Based Care because I love working with people who are sick because that experience gives me sense of fulfillment and satisfaction”. (Home Carer 3)

“No, I was not forced by anyone but did volunteer myself because there are many people who are sick”. (Home Carer 6)

“No, I cannot say I was forced, because you cannot become a career if you don’t have the passion of helping other people. It was the passion that has

driven me to conduct such a work. You know, if you are a carer you must not put money first but should be there to serve people. You must deny yourself and put the needs of other people first. Yes I agree that nothing you can do without money. But otherwise the work of home carer is all about volunteering. The work of a carer is like that of a nurse or doctor because it is a calling. If you don't have the heart for serving people, you cannot enjoy doing this work. It must be something that you love to do and not forced. The benefits of doing home based care work are that you learn to persevere under difficult circumstance and hardships. You also experience joy, peace and happiness in your soul. You experience sense of fulfillment and achievement". (Home Carer 4)

Another caregiver cited lack of family support in care services as the driving force that compels her to do the job willingly, fully and tirelessly. However, the love for caring of sick people compels her to give time resources.

"There are many people who are sick out there; it is a challenge that you must open your heart to help them, more especially the HIV/AIDS clients". (Home Carer 6)

"Hmmm----- it was difficult really, but since I love this job and having realized that people are suffering and need help, you offer yourself to render the service freely. Sometimes the person is staying alone and there is no one to assist him. It is then I decided that I must volunteer to help sick people in the community. As a volunteer you don't get paid but because you love your work you continue doing that job. I then told myself that I must go and do this work. That is how I got started with home based care". (Home Carer 5)

HIV/AIDS infects and affects many people in poor communities. As a result there are many people who are ill with no one to take care of them. The government of South Africa also promotes community participation as a strategy for effective HIV/AIDS management (Campell, 2009). The following citation supports the statement:

"As you know that our government has acknowledged the need and value for caring people living with HIV/AIDS in their homes. In our community there are many people who are infected or affected by the pandemic. We realized that after we were taking care of the orphans and doing HIV Awareness to the community, the bedridden and terminally ill people living with HIV/AIDS are neglected and helpless in their home. It is when we decided to begin with home based care in 2008 January". (Coordinator)

One caregiver pointed out that doing home based care services is like being a doctor or a nurse. It is more of a calling than working for an income. This is demonstrated by the following quote:

“I love being a carer because I wanted to become a nurse, I wanted to see myself helping people, especially those people who are sick. My mother was suffering from cancer and my sister was also infected with HIV/AIDS. That’s where the passion develops. So I helped them and it was a nice experience I felt that because I was able to help my family then I can do it in the community also”. (Home Carer 4)

Caregivers acknowledged that caring for those who are HIV positive is a welfare service. Money should never be the priority. It is a service aiming to help vulnerable people suffering from illnesses such as HIV/AIDS. They prepare themselves to render the service freely. The care workers acknowledge that UWCO is a welfare organization aiming to help vulnerable people. This is demonstrated by the following quotes:

“One thing that you need not to forget is that the organization is all about welfare. It is a Non Profit Organization (NGO). Therefore the mandate is all about helping people who are infected and affected as a result of HIV/AIDS”. (Home Carer 1)

“The Umtha Welanga is to help communities cope with and take care of the increasing numbers of families and children infected and affected by HIV/AIDS. The organization seeks to provide a loving and supportive link between terminally ill parents and the future caregivers of their children, facilitating a relationship between the biological parent and the intended foster parent. The other service is called foster care programme whereby we recruit & screen foster parents, train staff, foster parents , support groups and volunteers , have registered social worker and child care workers, we do income generation skills, legal placement processes, assistance with state child care grants” (Coordinator)

In Africa, home and community care depends heavily on the work of volunteerism (Harding & Higginson 2005). When volunteer care workers are utilized, the cost and expenditure remains lower, but it also enables communities to work together in supporting each other, establish the spirit of “ubuntu” (humanity), raise awareness and promoting

tolerance and acceptance (UNAIDS, 2000). Volunteers are playing a significant role; however strengthened systems are needed for the appropriate support and management of the home based care workers (Scheineider, *et al*, 2008).

It is clear that care workers volunteered to render care services and are driven by love and passion to serve their communities. They make a choice voluntarily to assist those who are ill in their communities. Caregivers understand that there is no financial remuneration in this kind of job, but still offers themselves as volunteers for the wellbeing of the community. Although they acknowledge that they encounter financial difficulty, caregivers are willing to serve their communities with pride to alleviate the pain and suffering caused by HIV. As more parents are dying and leaving behind their children, these orphans put pressure on older relatives who become their primary carers; they may have to relocate from their familiar neighborhood; and siblings may be split apart, all of which can harm their development. This responsibility puts pressure and demands to the relatives, caregivers, community and society at large.

4.4.4 Overwhelming and demanding experience

The tasks and actions performed by care workers are depressing and overwhelming. Some families that are being cared for live in extreme poverty. The client sometimes lives alone with no other family member to look after him/her. In some households, people are not warm and friendly and can shut the door to show care givers that they are not welcome. Members of the family who are overwhelmed and burdened by care work take out their frustrations on the home based caregivers. This creates an overwhelming and traumatic experience to the care worker as illustrated by the following quote:

“Like, when we are doing home visits; sometimes you face some hardships sometimes from the family members. Example, there was a time when I visited this mother in the family, she started to swear at me, saying that I’m sick and tired of UWCO who keeps on making empty and was saying I don’t want to hear about UWCO promises, and I don’t want to hear about it. She was also swearing at me” (Home Carer 2)

When asked what are the most overwhelming and demanding experiences they have encountered during care giving services, they articulated the following:

“Sometimes you are not welcomed and they will ask you many questions such: Who said we have got a sick person in this house? Who said we need your help? They can also close the door to show that you are not welcome”. (Home Carer 2)

“The most worrying thing is that when you visit people in their houses, you find that living conditions are very poor. This is one of the most troubling experiences you face. There was also one time when I visited the male client who was living on his own without family members or friends around. I was afraid of being raped”. (Home Carer 3)

“It is challenging out there in the community because you work with different people. The emotional experience that I once experience was after I have tried to help the client by washing him, the next thing he died. Emotionally, I was disturbed and started to feel guilty, for I did not understand how that person can pass away after washing him. In the organization, we work as a family, so if there is any problem we sit down and try to resolve it. If we cannot solve it, then the coordinator will solve it”. (Home Carer 4)

Sometimes the family is not welcoming toward the caregiver and they are even insulted by frustrated household members. At times clients also refuse to be assisted by care workers whom they are not familiar with. Evidence of this kind of behavior was documented by a caregiver through the following quote:

“The client will refuse to be helped because the one she knows didn't come. She will tell you that I will only bath when that one comes. So it is a challenge really. You really need to be down until the client agrees. They will take advantage of us because they think we get paid for such services. We are only there to assist". Sometimes you are not welcomed and they will ask you many questions such: Who said we have got a sick person in this house? Who said we need your help? They can also close the door to show that you are not welcome”. (Home Carer 5)

The coordinator expressed pain and suffering when witnessing misery and helplessness from the clients and their children. They are affected emotionally and psychologically, as it is mentioned by the coordinator in the following quote:

“It is a very emotional experiences that you go through when working with people who are HIV/AIDS positive, but because when we do training we are empowered that this is a journey whereby you need to be strong for the client and we are there to give them hope. But anyway as time goes on you become strong”. Example, there was this one lady who was in the hospice, by then she couldn’t speak properly and the only solution was to read her lips or give her the paper to write on. She asked me to promise her that I will take care of her 8 year old daughter”. (Coordinator)

Caregivers are confronted with psychological and emotional challenges from both the client and family (Ankitola, 2008). Feelings of guilt and self blame are experienced by caregivers due to the overwhelming experiences they encountered. Caregivers reported feelings of emotional drain, being stressed, exhausted and overwhelmed and some thought of giving up their jobs (Dangeid, Sedumedi & Duckert, 2009).

Home based care workers do not only suffer maltreatment and distress from the clients and family members, clients sometimes also refuse to disclose their status and insist that they are not sick due to lack of trust.

4.4.5 Lack of disclosure and trust

The UWCO works in conjunction with the family only after clients have disclosed their status to the family. When there is no cooperation with the client and family members, this creates a difficult condition for caregivers to support the client. It becomes difficult to assist people if they do not disclose their status. This is facilitated by the fact that there is a lack of trust from the clients and family members. HBC encourages clients to accept and disclose their status which enables them to cope in terms of positive living for the future of the family and placement of children. They also facilitate disclosure through HIV/AIDS education with the family, community and when visiting the clinics.

When conducting door to door visits, some caregivers have pointed out that the family does not feel free to disclose the status of the infected family member. This is demonstrated by the following quotes:

“Otherwise most of them they don’t disclose their status, and you can only get the information from next door. Still you need to wait until they disclose and allow him/her for the permission to do home care. Other instance the client will be in denial. This is not easy at all”. (Home Carer 5)

There are many challenges that we face, for an example, it can be difficult to collect documents from the people for the foster care, because they will ask you why do you want the documents and it becomes difficult to help a person without documents e.g. death certificate. Some families are not welcoming when you are doing community work.” (Home Carer 1)

The appropriate disclosure of one's HIV status results in a sense of empowerment and leads to a decrease in stress (Adams-Tufts, Wessell & Kearney, 2010). Furthermore, disclosure is appropriate when it is done under safe circumstances and with persons who need the information to provide proper or relevant health care services to them or to protect others (i.e. acting responsibly with their sexuality). In the study conducted by Ankitola (2008), it has been found that some home based caregivers are denied access to homes fearing that they would disclose the status to the community and begin to stigmatize the affected individuals and their families. It can further be highlighted that some families would deny that they have a sick person in the house, while others insulted the volunteers, pointing out that the care provided is of less or no value.

It can be concluded when there is lack of disclosure and trust from the family and clients toward the care workers; this creates difficult conditions for them to perform their tasks and duties. Openness and disclosure make the work easier for the care workers. Without being granted the permission or given the consent to perform care duties, care workers are unable to operate. Furthermore, care services present many risks and dangers to the caregivers.

4.4.6 Risk faced by caregivers

The home based caregivers of UWCO are only females and mostly conduct home visits unaccompanied. It is mentioned that they feel unsafe, vulnerable and exposed to rape by the male clients who are staying alone without family members. It is very risky when visiting the client for the first time.

Sexual harassment can be directed to both male and female; however, women are the most targeted. A home carer states her experiences regarding this risk:

“There was one time when I visited the male client who was living on his own without family members or friends around. I was afraid of being raped”. (Home Carer 3)

Preventive measure can be used such as sending two home based caregivers for a home visit instead of one caregiver to minimize the possibility of a woman becoming a target opportunity of rape and robbery, since the offender usually waits until the potential victim is vulnerable or isolated (UNAIDS, 2008).

Another participant also highlighted that it is not safe to walk in the location alone because there is a high rate of unemployment in the location which results in a high rate of crime and violence.

“When we are doing visits, it is very risky sometime, because you are visiting the person for the first time and it is very risky and dangerous to ask people because of the crime rate around the location. The other thing is that it is not safe to walk around the location”. (Home Carer 2)

The distance travelled by foot can be far and isolated without public transport. Caregivers sometimes even get lost while on their way to visit a client since they are afraid to ask people on the street for directions. As a result, caregivers become vulnerable to the crime in the location and their safety is therefore compromised. The following comment was voiced:

“I think with home visit we do experience lots of challenges. We are in great risk because sometimes you don’t know the address to that particular home. You will travel long distance asking people of the direction, trying to find the location. We even get lost sometimes and it is very dangerous because in the location it is not very safe, there is high rate of crime. Some places are very far and isolated” (Home Carer 5)

Criminal activity has become a significant threat to the safety of aid workers and such activity takes different forms such as assault, hijacking and robbery (Gold *et al*, 2004). Some caregivers highlighted that they perform care work under threatening conditions and are exposed to infections; however, the organization ensures that they are using protective measures such as gloves and masks when performing client care. The following quotes support the above statement:

“Okay, we are working under risk, but anyway we need to protect ourselves by using mask and gloves. It is very important that we need to be there”.
(Home Carer 4)

It can be concluded that caregivers are exposed to various risks and hazards. They feel exposed to criminal activity, unsafe and are vulnerable to gangsters in the community. They are afraid of robbery and being raped. The caregivers can contract HIV/AIDS while on duty if not properly covered and protected by gloves. In rendering home based care effectively and competently, it is of paramount importance to create conditions whereby caregivers are fully recognized for their critical role of care, affirmed and given adequate support from the state and health professionals. Finally, the caregivers’ concerns and worries stem from lack of recognition by the government.

4.4.7 Lack of recognition

Recognition is a prerequisite for the acknowledgement of another human being of one’s emotions, knowledge or skills, all founding competencies in health and care work. This measures the worth and trustworthiness of these competencies through the attitude of the other. Acknowledgement allows the subject to display and use her emotions, knowledge and skills and thereby to reflect on them, change and develop them (Liveng, 2010).

Home based care volunteers are dissatisfied regarding the lack of recognition to their work. It is the service which is undervalued and they experience exploitation without normal rights or benefits such as leave, maternity benefits and a pension by healthcare authorities and communities (Schneider *et al*, 2008). The following citation supports the above comment:

“My concern is that the government should start to recognize the services of home care seriously by ensuring that we are registered, recognized and paid well because this task drains a lot of energy”.(Home Carer 2)

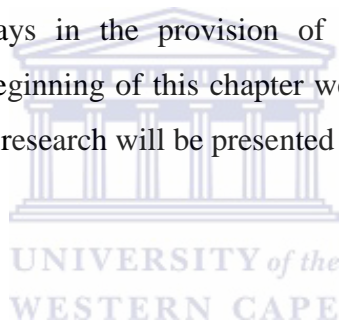
The roles and responsibilities assumed by caregivers are unrecognized and undervalued (Pallangyo & Mayers, 2009). Ogden, *et al* (2004) supported that the home based care work is the kind of service usually taken for granted and undermined by the government and the NGO's because it is usually viewed as the activity or role to be performed by women to sustain their families, communities and nations. Therefore, when care work remains invisible to the society, even the care workers are taken for granted. Caregivers, whether doing formal or informal care work need to be acknowledged as part of the health care system to the response of epidemic requiring financial, medical and social support (UNAIDS, 2000). It can therefore be suggested that carers should receive proper recognition for their work, experience, knowledge by the government since lack of recognition to their services can affect carers' performance.

4.5 Conclusion

The demographic data revealed that all the home based caregivers are females resulting in a gender imbalance in care giving services of UWCO. The participants in this study had limited education, were not formally employed, and had little time for income-generation activities. UWCO aims to help communities cope with and take care of the increasing numbers of families and children infected and affected by HIV/AIDS. Caregivers volunteered to render care services and are driven by love and passion to serve their communities. When all the sectors are involved in care giving services and are working in partnership with each other, maximum service delivery becomes achievable.

This research has indicated that home based care givers are vulnerable to many hazards such as dangers of rape by male clients who live on their own, crime such as robbery whilst they are walking alone in the location, risk of contracting HIV while conducting their duties without properly covered by gloves. In some instances, family members who are burdened and frustrated by care duties rendered to their relatives insult the caregivers. Lack of disclosure by clients and family members creates a difficult condition for caregivers to conduct home based care services. It is a very emotional experience when working with PLWHA. However, training enables them to be strong and they give their clients hope. There is a lack of proper recognition by the state for the care service provided by volunteers.

Chapter four documented the results of the study that aimed to determine the role a community organization plays in the provision of home based care services. The objectives indicated at the beginning of this chapter were discussed. The conclusions and recommendations for further research will be presented in chapter five.



CHAPTER 5

CONCLUSION AND RECOMMENDATIONS

5.1. INTRODUCTION

The research was undertaken to explore the challenges faced by UWCO in the provision of HIV/AIDS home based care. In the previous chapter the findings of the study were presented and discussed in detail. The aim of this chapter is to draw conclusions, provide recommendations and suggest further research based on the findings of the study.

5.2 SUMMARY OF THE FINDINGS

The qualitative findings regarding the role of Umtha Welanga Community Organization with regard to home based care provision and challenges experienced by home based carers are highlighted. The conclusion was drawn based on the objectives of the study.

5.2.1 Demographics of the participants

The demographic characteristics of the caregivers profile revealed that their ages were between 20 - 40 years. All the caregivers were females. Fifty percent of the sample was never married and are staying with relatives. In relation to education, all the caregivers passed grade 12 and a few proceeded to tertiary education.

5.2.2 Home Based Care provision of Umtha Welanga Community organization

Umtha Welanga Community Organization aims to help communities cope with and take care of the increasing numbers of families and children infected and affected by HIV/AIDS. The home based care services program was introduced at Umtha Welanga Community Organization in January 2008. HBC supports the client at home. This is followed by making a referral to the hospice if the client qualifies to be placed in the institution. UWCO works in conjunction with the social workers of the Western Cape.

HBC is responsible for making assessments of the living condition of the client, orphaned children if they have food, school uniforms and other basic needs.

Home based caregivers are supported by social workers on a weekly basis. This is to ensure there is adequate and effective quality care service delivery. The supervisor accompanies them at least twice a month while they conduct home visits. Supervisors build mutual relationships between caregivers and their clients together with the families. HBC workers are satisfied with the support and recognition they get from the supervisors.

Umtha Welanga Community Organization does not offer any formal training to caregivers and most of the HBC staff members are trained by other institutions such as the Department of Health and Social Development to ensure competent skills. This training provides them with skills such as counseling, care of psychosocial needs, medical and nursing needs of the client and family needs such as care of children, legal advice and assistance. HBC providers assist people on a level that is closer to the clients' understanding. Through this interaction the caregivers develop the necessary skills, which are required in rendering services in their community. Some of the skills being utilized in caring are acquired informally such as when accompanying a fellow home base caregiver on home visits.

Home based care workers are mainly volunteers committed to care giving services and are motivated by the positive aspects, such as feelings of fulfillment and satisfaction when rendering care services. Some caregivers had life changing experiences such as having HIV positive family members and this motivated them to become loyal caregivers, and rendering care services in the community. Volunteers are often as poor as the households they are serving.

HBC workers are responsible for taking care of the terminally ill clients, to give people hope, helping to bath and feed clients, and also to administer medication and treatment competently and safely. The role of home based caregivers will continue to be essential to the care of HIV/AIDS clients.

The organization creates a network and partnership with other institutions to work effectively. This is done by establishing relationships with the families, schools, and other CBO's and NGO's, churches, hospices, private sectors and government departments to work in corporation with each other. UWCO works in partnerships with families, churches, schools, communities, other organizations, institutions and departments to ensure positive impact of caring for one another which is driven by 'Ubuntu' principle within the communities.

5.2.3 Challenges experienced by community home based organization

The aim of exploring the challenges faced by UWCO in the provision of HIV/AIDS home based care was to highlight the main areas of concern. The study concluded that home based caregivers are faced with various challenges when rendering care services. It has been established that there is a gender imbalance in UWCO. The organization is predominantly constituted by women from the management to the home based caregivers. There are only three males who are involved in managerial positions and none participating in care giving services. Moreover, most clients who disclose their status are women, thus resulting in more women clients who receive care services compared to men.

In general, UWCO greatest challenge is the finances in the operation of the organization. The management acknowledged that money is the greatest challenge they experience in the organization for the smooth running of the operation. The organization also experiences negative response with funding applications. As a result, caregivers cannot be sustained permanently in HBC duties unless the remuneration is adjusted to suit their living conditions. The main concerns and worries of caregivers are insufficient salaries. Poverty and a high rate of unemployment were found to be the driving force behind these women's involvement in home based care. Lack of money creates feelings of dissatisfaction to the caregivers with regard to payment of salary. Regardless of low payment received, caregivers expressed a sense of satisfaction and fulfillment to their work.

However, most of the care workers acknowledged that home based care is a voluntary service and it can only be performed by someone with love and passion. Home-based care promotes community participation, while empowering family and community members with care giving skills. Moreover, in a poor resource setting like Khayelitsha where finance is a predicament to sustain and pay workers, it is important to promote the use of voluntary service by community members. Volunteers provide the care that gives PLWHA some hope, of being cared for in a familiar environment such as their homes with respect and dignity. Clients feel more comfortable with someone from the same community than a stranger from a “big” hospital facility. Therefore, home based caregivers are practical instruments to give HIV clients hope through love and support.

Moreover, there is a lack of proper recognition by the government for the care service provided by volunteers. Registration by the states is vital in order to receive appropriate remuneration. The role of home based caregivers will continue to be essential to the care of PLWHA in South Africa. These caregivers provide the care that gives PLWH some hope, if not of survival, of being cared for with love and dignity. Home based care workers are normal human beings driven by love and passion to help people who are sick in their families and communities, yet they are disheartened in their work since they lack recognition and support from the government.

Lack of disclosure and trust from the family and clients toward the care workers, creates difficult conditions for them to perform their tasks and duties. Openness and disclosure make the work easier for the care workers. Without being granted the permission or given the consent to perform care duties, care workers are unable to operate. Furthermore, care services present many risks and dangers to the caregivers such as being susceptible to criminal activity, feeling unsafe and vulnerable to gangsters in the community. They also express fear of robbery and being raped by criminals in the community. They are also vulnerable of rape by male clients who live alone. The caregivers can contract HIV/AIDS while on duty if not properly covered and protected by gloves and therefor compromise their safety and security.

Caregivers now and then experience negative treatment by clients and family members. Family members are on occasion burdened and overwhelmed by care services they perform toward their client. When they are frustrated, they swear on care givers, claiming that UWCO makes empty promises without fulfilling them. This treatment weighs down and discourages caregivers to perform their activity in an enthusiastic manner.

However, despite the challenges faced by HBC givers, there are benefits gained by both the caregivers and client. It enables the client to be cared for in a familiar environment of their homes by their relatives. Caregivers accumulate diverse experiences because they do not only learn about the home based care program, but also become more knowledgeable with other programs such as child headed households to assist and ensure that children have got basic needs such as food, proper shelter, school uniform, and are healthy. They experience satisfaction, joy and fulfillment after assisting someone who is sick and helpless.

5.3 RECOMMENDATIONS

In the next section the recommendations and further research will be highlighted.

- The government should acknowledge care as a priority human need and encourage both men and women to show commitment to the caring work.
- A limitation in this study is the fact that only women were participating in home based care service. More males need to be recruited for the care services to break the stereotype.
- Government must also ensure that home based care workers get recognition, credit and support for their valuable contribution.
- Training for HBC employees need to be extended to expose and add more skills. This will ensure that care workers are well equipped to perform care services.
- Home based care workers must become registered and paid better salaries by the government.
- Volunteers should work in pairs to ensure safety, security and support.

- The government should minimize the strain on home based caregivers by recognizing and linking home based care workers with the district health systems.
- Policies need to be strengthened or reformed to achieve comprehensive and integrated care solutions to sustain informal caregivers.



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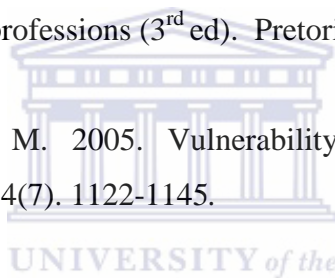
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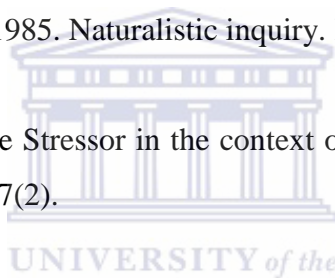
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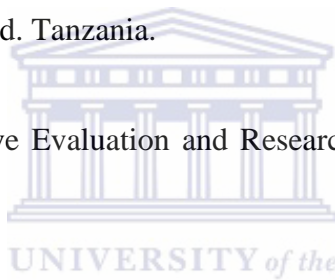
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APPENDICES

Appendix 1: Permission letter

Appendix 2: Informed consent form

Appendix 3: Questionnaire about demographic information

Appendix 4: Interview guide for Home based caregivers

Appendix 5: Interview guide for management and staff



Appendix 1

FACULTY OF COMMUNITY AND HEALTH SCIENCES

Permission letter

Letter Requesting permission to conduct Research

The Managing Director
Umtha Welanga Community Based Organization
Masiphulisane Center
E 505 Scott Street
Khayelitsha
7784

Request for permission to conduct Research

I, Rendani Marcia Ramuhaheli, a Master's student in Human Ecology at the University of Western Cape, request permission to conduct research at Umtha Welanga Organization in Khayelitsha. My research study aims in exploring the challenges that the Umtha Welanga organization faces when providing HIV/AIDS home based care services. The objective of the study is to access current home based care of the organization and to identify models of intervention which appeared to be effective and sustainable.

A qualitative research design will be used involving the home based care workers and the managers. In-depth interview and simple observation will be used to collect the data with the participants. Data will be analyzed by using thematic content analysis. The significance of the study is that it will help contribute knowledge to the organization that will help home based care services. The research will be conducted on the first week of September during the University vacation.

Please do not hesitate to contact me for further details.

Yours faithfully

Rendani Marcia Ramuhaheli

Cell: 082 630m 8007

E mail: rendanimarcia28@gmail.com

Appendix 2

INFORMED CONSENT FORM

The study has been described to me in a language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Participant's Name

Participant's Signature

Date

Witness's Name

Witness Signature

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:'

Dr. C J Erasmus

Department of Human Ecology

University of the Western Cape

Private Bag X17, Bellville, 7535

Telephone: (021) 959-2760

Fax: (021) 959-3686

Email: cjerasmus@uwc.ac.za

APPENDIX 3

QUESTIONNAIRE: DEMOGRAPHIC INFORMATION

Title: A case study exploring the challenges of providing HIV/AIDS home based care services by Umtha Welanga Community Organization

Interview Number.....

Date of interview

Please answer all the questions below by placing a tick in the appropriate box or filling in the space provided.

DEMOGRAPHIC DATA



1. Age

15-19 years	
20-29 years	
30-39 years	
40-49 years	
Others	

2. Marital status

Single	
Married	
Widowed	
Separated/Divorced	
Others (specify)	

3. Educational status

Primary	
Secondary	
Tertiary	
Others (Specify)	

4. Religion

Christian	
Muslim	
Buddhism	
Africanism	
Others (specify)	

5. Apart from serving the organization, are you employed somewhere?

Yes	
No	



Appendix 4

INTERVIEW GUIDE FOR HOME BASED CARE WORKERS

1. How long have you been working as a home based carer for this organization?
2. How did you get involved with this organization?
3. Did you receive any training before beginning as home based care worker?
4. What type of training did you receive?
5. How does the training assist you in providing care services?
6. How much support do you receive from the organization where you work as home based carers?
7. What kind of support do you receive from the organization?
8. What challenges do you experience with working with this organization?
9. What do you think are the benefits of working for this organization?
10. Do you know who to contact if you have any problems?
11. Why have you chosen to do home based care out of all the services?
12. What do you think are the benefits of conducting home based care?
13. Did you voluntarily chose to perform home based care or were forced by circumstances?
14. Discuss the attitudes of the managers and administrators towards home based care workers?
15. What is the worst part or the thing that most concerns or worries you about being home based carers?

Appendix 5

INTERVIEW GUIDE QUESTIONS for the MANAGEMENT and STAFF:

Exploration of the challenges facing Umtha Welanga Community based organization in the provision of home based care services.

1. What are the goals and objectives of home based care as provided by this organization.
2. What is the core business of this organization?
3. Where does it operate?
4. What services does your organization provide, except for home based care?
5. What other organizations does this organization link to in the area?
6. What categories of staff / volunteers are there in each function?
7. Where does it get its funding from?
8. What is the management structure?
9. Who does the management account to?
10. What drives the organization to render home based care services for the community?
11. When did home based care services begin?
12. How many staff workers are conducting home based care?
13. What are the challenges of home based care as experienced by the organization?
14. What are the benefits of home based care?
15. Are there any support systems for the home based care programmes from the community and government?
16. How is the response of the community members towards these services your organization provides?
17. Do you encounter any financial problems with this programme? What are those problems?
18. What are the physiological demands that you experience as an organization? Example: anxiety, stress
19. What have you done about these problems?

20. Do you experience any emotional/physical problems? What are those problems?
21. Does the community volunteer to help with home based care?
22. How often the home is based carer supervised?
23. Does the organization have a training plan in place for updating skills of staff?
24. Is this an ongoing process?
25. Is training mainly in house?
26. What format does this training take?
27. What type of training does the home based carer receive?
28. What is the duration of the training?
29. Is there any formal curriculum in place?
30. How was this curriculum derived?
31. What percentage of the training is practical?
32. What are the priority areas for improvement in management?
33. What is your overall appraisal of the quality of care provided by HBC?
34. What is the strength of its quality of care?
35. What are the weaknesses of the care domain?
36. What are the priority areas for improvement within the quality of care?
37. Does the organization interact with other organizations in the area?