

**EDUCATIONAL NEEDS AND ASSETS OF  
HOME-BASED CAREGIVERS FOR  
HOME-BOUND CHRONIC PATIENTS - A CASE STUDY**

by

**DAYCE MAKAKOLE CHUENE**

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**SUPERVISOR: Ms PD Moloko**

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## DECLARATION

I, Dayce Makakole Chuene, hereby declare that this mini-dissertation submitted to the University of Limpopo for the Masters degree, has not been submitted previously for a degree at this or any other University and that it is my own work, and that all the sources used or quoted have been indicated and acknowledged by means of complete references.

Signature .....

Date .....

## **DEDICATION**

I dedicate this piece of work to my husband Ramoshweu, my two children Phillip and Mahlako, my daughter in law, Maria, and grandson Ramoshweu, for their never ending love and support during the period of my study. They understood that my absence was for a good cause and kept the light burning.

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## ACRONYMS

ABET	Adult Basic Education and Training
AIDS	Acquired Immune Deficiency Syndrome
AHCWs	Ancillary Health Care Workers
ART	Anti-Retroviral Treatment
CBOs	Community Based Organisations
CCHBHC	Comprehensive Community Home-Based Health Care
CHBC	Community Home-Based Care
CHW	Community Health Workers
DoE	Department of Education
DoH	Department of Health
DSD	Department of Social Development
EPWP	Extended Public Works Programme
FBO	Faith Based Organisation
HBC	Home-Based Care
HBCCM	Home-Based Chronic Care Model
HIV	Human Immunodeficiency Virus
HWSETA	Health and Welfare Sector Education and Training Authority
NACOSA	Networking HIV/AIDS Community Of South Africa
NGO	Non-Governmental Organisation
NPO	Non-Profit Organisation
PLWHA	People Living With HIV/AIDS
SAQA	South African Qualification Authority
SETA	Sector Education and Training Authority
TB	Tuberculosis
WHO	World Health Organisation

## **ABSTRACT**

This report describes the research conducted at Kgotlelelang Basadi Home-based Care centre, in the Capricorn District Limpopo Province of South Africa. The centre serves four villages: Ngwanamago, Makata, Matobole and Thaba.

### **Statement of the problem**

It seems the home-based caregivers of chronic patients at Kgotlelelang Basadi HBC centre do not have the necessary qualifications, knowledge, skills, and health care and protective resources such as gloves, thermometers and masks. It looks like the home-based caregivers are not adequately and continuously trained as there are always new discoveries and developments with regard to the treatment of diseases. It appears they perform their duties without sufficient support by relevant institutions like clinics and hospitals. Furthermore, it appears the home-based caregivers are not recognised, and are also undermined.

The aim of the study is to explore the educational needs and assets of home-based caregivers for homebound chronic patients at Kgotlelelang Basadi Home-based Care centre. After establishing the educational needs and assets of home-based caregivers I recommended the formulation of possible relevant educational programmes. In an attempt to achieve the said aims, the following research questions were formulated and put forward in chapter 1.

### **Objectives**

- To establish the existing qualifications of home-based caregivers for home-bound chronic patients at Kgotlelelang Basadi HBC Centre.
- To determine the relevancy of the existing educational programmes of home-based caregivers for home-bound chronic patients.
- To contribute towards formulating relevant educational programmes of home-based caregivers for home-bound chronic patients.

## **Research questions**

What are the educational needs and assets of home-based caregivers for homebound chronic patients at Kgotlelelang Basadi Home-based Care centre?

The following sub-questions were derived from the main question:

- What are the existing qualifications of home-based caregivers for homebound chronic patients at Kgotlelelang Basadi Home-based Care centre?
- How relevant are the existing educational programmes of home-based caregivers for homebound chronic patients?
- What relevant educational programmes can be devised for home-based caregivers for homebound chronic patients?

## **Research design and methodology**

A qualitative research approach was used, with some elements of qualitative aspects such as number of caregivers who were trained. A single case study design was employed to gain an in-depth understanding of caregivers' educational needs and assets.

Non-probability purposive sampling was used to ensure that participants are selected based on their knowledge and experience. Data was collected through document analysis, observation, semi-structured one-to-one interview observation, and focus group discussions.

Chapter 2 outlines theoretical framework based on relevant literature on the research topic. I formulated assumptions on the educational needs and assets of home-based caregivers based on proper qualifications, relevant adequate training programmes, administration and managerial experiences, monitoring and support, and funds and resources. Key concepts were also defined in this chapter.

Chapter 3 presents the research methodology. The research design, data collection and analysis used for this study are clearly explained. This study was qualitative in nature and took the form of a single case study design, which allowed a detailed and extensive study of the case as it exists in its natural setting.

Chapter 4 outlines presentation and analysis of findings obtained through document analysis, observation, and interviews with various respondents. I formulated variables from the assumptions that were presented in my theoretical framework and from the interview guide.

## **Findings**

It was found that home-based caregivers at Kgotlelelang Basadi Home-based Care centre have some educational needs and also possess assets that could enable them to be educated through training programmes so that they can be able to offer quality service to the homebound chronic patients. Those educational needs and assets are based on age and gender, educational level of caregivers, proper qualifications, available training programmes, administration and managerial experiences, monitoring and support, finances, resources and infrastructure.

Chapter 5 constitutes the conclusions and recommendations which are based on the research question and findings of this study. The recommendations might help in addressing the educational needs of caregivers and realising their educational assets. I recommend further study on the educational needs and assets of home-based caregivers for homebound chronic patients in urban areas and townships.



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# **CHAPTER ONE**

## **INTRODUCTION AND BACKGROUND**

### **1.1 Introduction**

This mini-dissertation is a report on the educational needs and assets of Home-based Care (HBC) at Kgotlelelang Basadi Home-based Care Centre at Ngwanamago village in the Limpopo province. The research falls under Health Adult Education which is one of the four research pillars of the Community and Continuing Education Unit at the University of Limpopo.

In this chapter, the background of the study is outlined in terms of HBC looking at the different countries guided by the findings from other studies. The findings of other global studies on HBC are presented, focussing on the Southern African region, South African provinces, and finally the Capricorn District of the Limpopo Province. The rationale for HBC is highlighted to show the origin of HBC in South Africa and neighbouring countries. The socio-economic profile of the four villages is highlighted to provide a clear picture of the area where the study took place.

The problem which prompted the researcher to undertake this study is presented in this chapter together with the aims, objectives and research questions. The significance of the study, how the findings will benefit different people and organisations is outlined. The delimitation of the study and ethics that adhered to during the research project are highlighted.

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### **1.2 Background of the study**

The South African Department of Health (DoH) (2001) has adopted the World Health Organisation's (WHO) definition of HBC as "the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health, including care towards a dignified death." Home care services include categories such as preventive, promotive, therapeutic, rehabilitative, long term maintenance and palliative care.

According to Stewart, Carrington, Marwick, Davidson, Macdonald, Horowitz, Krum, Newton, Reid, Kai Chan, Scuffham (2012:16), who conducted a randomised centred study in America, HBC results in the reduction of patient hospitalisation. Ama (2011:34) states that HBC in Botswana was instituted in 1995 in order to alleviate overcrowding in the health facilities because of the increased number of HIV/AIDS infections. She further indicates that HBC takes place at home and it is usually practiced by volunteers and family members of the patients. Akintola (2006:238) conducted a similar study in the Marianhill area in Durban, KwaZulu-Natal in South Africa, and established that Home-based Caregivers (HBC-givers) provide several services like basic nursing care, spiritual and moral support to patients and their families.

Muwaniki (2010) researched the challenges faced by Phuthanang HBC in providing care and training at the Mankweng Township in the Capricorn District in the Limpopo Province, South Africa. He focused on the challenges that HBC-givers experience when providing care to HIV/AIDS patients, and training both the patients and their families on care and associated skills, such as growing vegetables, baking, sewing, health education and hygiene.

Unlike Muwaniki's study, which focuses on the challenges faced by home-based caregivers in providing care and training, the present study explores the educational needs and assets of caregivers for home-bound patients who suffer from different chronic diseases. Muwaniki's study also focussed more on caregivers caring for HIV/AIDS patients, whereas this study focuses on caregivers caring for home-bound patients who suffer from various chronic conditions, not only HIV/AIDS. Furthermore, Muwaniki (2010) studied HBC-givers in a township or semi-urban setting, which is densely populated and characterised by different cultures, beliefs, norms and values. The research study was conducted on HBC-givers in a pure rural setting which is sparsely populated, where people adhere strongly to and share the same cultural norms, values, beliefs and practices, which could have an impact on HBC practice. Additionally, the literacy level in rural areas may be lower than that of a township, and thus impacts on HBC. The socio-economic profile of a rural area and a township also differs and may thus affect HBC-giving differently. However, the aforementioned studies are related in the sense that, for caregivers to provide care and training, they need to be educated, adequately trained and skilled. One of Muwaniki's findings

(2010:61) is the inadequate training of caregivers, which hamper their care giving, and as such the educational needs and assets of HBC-givers had to be explored, more especially due to new discoveries made by scientists with regard to diseases, medication and care. Muwaniki's other findings are that the HBC-givers experience many problems such as lack of funds, limited community participation, stigmatisation, infrastructure, equipment and sanitary facilities.

According to the South African DoH (2001) the spread of HIV/AIDS resulted in many people being admitted into hospitals, hospices or other institutions for care, which became a burden to the South African health care resources. HBC thus provides back-up for people who need extended care at their homes. The rapid spread of HIV/AIDS prompted the South African DoH to introduce HBC for patients who cannot be admitted into hospitals or need to be cared for at home.

Much was done on HBC and HIV/AIDS in urban and township areas where patients have access to institutions such as hospices. The research for this study was conducted in a rural area where people often do not have access to clinics or have to travel to another village with a clinic. The study focused on the educational needs and assets of HBC-givers who care for home-bound patients suffering from different chronic conditions at Kgotlelelang Basadi HBC Centre at Ngwanamago village in the Limpopo province, and not just on HIV/AIDS.

The research was conducted in the context of the findings of other similar studies and relied on their findings to explore the educational needs and assets of HBC-givers who care for chronic patients at their homes.

### **1.2.1 Rationale for home-based care**

In many countries the health system does not cope with the high rate of people who need their services, especially hospitals. People are discharged from hospitals due to overcrowding and high healthcare costs even though they are still ill. These patients then need healthcare at home which can then be offered by family members, friends and the community.

HBC as defined by Van Dyk (2008:332) is “the care given in the home of the person living with HIV/AIDS.” The HI-virus has put the health system under tremendous strain in terms of personnel and financial resources, thus the introduction of HBC (Morwe and Ramaila 2012:229), which is often the best way care for someone with AIDS (Van Dyk 2008:333), is the best option. However, HBC is not meant for People Living with HIV/AIDS (PLWHA) only. Any person who suffers from any illness and is home-bound can benefit from HBC services. Hlophe (2006:193) argues that HBC programmes play a significant role in providing care and support for PLWHA and other chronic diseases and in developing the community. Hlophe (2006) is supported by Maphula and Mudhovozi (2012:133) who state that HBC offers services to people with physical impairment, including TB and HIV/AIDS.

In December 2001, the South African government published national guidelines on HBC and Community-Based Care (DoH 2001) to assist its implementation in the country. Although the guidelines recommend the involvement of a wide range of stakeholders, including the formal healthcare sector, implementation has placed the primary responsibility for care and support squarely on communities and the immediate families of the patients (Akintola 2006:237).

Due to the AIDS epidemic, the increase in non-communicable diseases, the complications thereof and an ageing population’s impending impact on communities and South Africa as a whole, it became necessary to consider how best to provide care for healthy people, people with diseases and their families.

In South Africa, HIV/AIDS, TB, and other chronic conditions are major challenges facing the government in terms of ensuring access to treatment and nutrition, providing psychosocial care and support to those infected and affected, as well as dealing with the increased burden on the welfare system (Department of Social Development (DSD) 2012:13).

According to Browning (2008) the Botswana government initiated CHBC programs in 1996 in order to transfer some of the responsibilities of care from the health facilities to families and the communities in which patients live. Furthermore, Browning (2008) also states that community HBC services, as a shift from hospital-based care, were adopted. Some of the Southern African countries also adopted the strategy of develop-



ing HBC services so that hospitals and other health care facilities could be relieved from being overcrowded.

Lindsey, Hirschfeld, Tlou and Ncube (2003:489) indicate that the rationale for the implementation of CHBC in Botswana is that the latter is the best method to care for many people with terminal illnesses. According to Jooste, Chabeli and Springer (2010:2) patients are often discharged from hospitals earlier or not even admitted because of a shortage of facilities and resources such as beds.

Owing to the public sector hospitals' lack of capacity to care for long-term patients, the community is increasingly asked to become more involved in HBC of the aged, HIV/AIDS patients, frail and terminally ill, patients that are physically disabled, and patients in palliative care. Hlophe (2006:192) states that HBC was developed as a strategy to limit the demands on the formal health system by providing care located close to people's homes and their families.

WHO (2003:22) indicates that many countries have limited health care resources, and further recommends that health services should be rationalised and volunteers be recruited to address identified community health problems. Furthermore, WHO (2003:49) attests that home visits provide an opportunity for health personnel to obtain a holistic picture of patients' living experiences in which illness is only one aspect of their lives. This enables health personnel to provide holistic care that meets physical, psychological, social and spiritual needs of the patients.

### **1.2.2 The socio-economic profile of the four villages**

The Kgotlelelang Basadi HBC Centre is situated at Ngwanamago village and also serves three other villages being Makata, Matobole and Thaba. These villages are approximately five kilometres apart from each other and are under jurisdiction of the Polokwane municipality in the Capricorn District of the Limpopo Province in South Africa. The nearest clinic which serves all four villages is the Zoetfontein Clinic, which is under the jurisdiction of the Seshego hospital in the Polokwane municipality.

These villages are characterised by unemployment and poverty. This is evidenced by many young unemployed people who roam the streets and spend most of their time in

bar lounges. The literacy level is evidently low, hence the mass literacy campaign initiated by the South African Department of Basic Education called Kha Ri Gude which is presently operating at the four villages. Old and middle-aged women are enrolled in basic reading and writing courses. However, each village has a primary and secondary school. Gardiner's study (2008), "Centre for Education Policy Development", revealed that in parts of Limpopo, 23% of women had received no formal schooling at all, 19% had left school below Grade 7 and 16% had stopped schooling after completing Grade 7.

### **1.3 Problem statement**

Although HBC-givers appear to offer one of the most essential services in the form of providing healthcare to patients at home, it seems that HBC-givers for chronic patients at the Kgotlelelang Basadi HBC Centre appear not to have the necessary qualifications or knowledge and skills; they don't seem to have the expertise of caring for home-bound chronic patients. A lack of knowledge and skills could hamper the healthcare services offered by the HBC-givers and without appropriate and adequate training, can endanger the lives of patients, since they deal with different kinds of diseases and conditions that need knowledgeable carers. Hlophe (2006:201) revealed that HBC-givers believed that they have insufficient training and lack the necessary knowledge and skills to perform their caring duties.

HBC-givers seemingly do not have health care or protective resources, for they visit patients without it. An HBC kit should include a thermometer, surgical gloves, an apron, soap, towel, disinfectant spray, and a dressing pack. Lack of protective resources put both patients and caregivers at risk of passing bacterial infections to each other.

Additionally, HBC-givers perform their duties without sufficient support by relevant institutions like clinics and hospitals. It is essential that HBC, or any kind of informal care, receives the necessary support from the formal health system (Tshabalala 2008:2). According to the researcher, HBC is such an important service dealing with people's lives that it needs people who are literate, adequately trained, supported by all stakeholders, and skilled and qualified in health care issues.

Furthermore, it appears that HBC-givers are not recognised and are also undermined because of their casual working conditions. Research is therefore needed to explore the educational needs and assets of HBC-givers.

#### **1.4 Aim of the study**

The aim of this study is to explore the educational needs and assets of home-based caregivers for home-bound chronic patients at Kgotlelelang Basadi HBC Centre in order to formulate possible relevant educational programmes.

#### **1.5 Objectives**

- To explore the existing qualifications of home-based caregivers for home-bound chronic patients at Kgotlelelang Basadi HBC Centre.
- To determine the relevancy of the existing educational programmes of home-based caregivers for home-bound chronic patients.
- To contribute towards formulating relevant educational programmes of home-based caregivers for home-bound chronic patients.

##### **1.5.1 Research question**

**What are the educational needs and assets of home-based caregivers for home-bound chronic patients at Kgotlelelang Basadi Home-based Care Centre in the Limpopo Province?**

##### **1.5.2 Sub-questions**

- What are the existing qualifications of home-based caregivers for home-bound chronic patients at Kgotlelelang Basadi HBC Centre?
- How relevant are the existing educational programmes of home-based caregivers for home-bound chronic patients?
- What relevant educational programmes can be devised for home-based caregivers of home-bound chronic patients?

## **1.6 Significance of the study**

The aim of the study was to explore the educational needs and assets of HBC-givers in caring for home-bound chronic patients at Kgotlelelang Basadi HBC Centre. The findings from this study will assist the centre and other similar centres by bringing awareness in terms of their educational needs and assets, and work on improving the services they offer to home-bound chronic patients.

The South African DoH must be aware of the educational needs and assets of the HBC-givers for home-bound chronic patients, understand their level of education, and thus develop adequate educational training programmes for them and also ensure that the necessary resources are in place. By educating HBC-givers, the standard of health care for home-bound chronic patients will improve and lead to the reduction of overcrowding in hospitals due to their deteriorating health and possible readmission to hospitals. The DoH can further realise the need for monitoring and support of the HBC-givers and also understand the challenges that HBC-givers encounter and formulate relevant policies regarding HBC.

Home-bound chronic patients will gain from this study since they will receive improved quality health care from appropriately trained caregivers. In addition, the study will be important to the community, for the intervention of the DoH can lead to carers performing their duties effectively, resulting in an improved health status of patients, which would relieve the whole community from the burden of caring. The findings will also add on the existing body of knowledge regarding HBC giving.

## **1.7 Delimitation of the study**

The research was conducted at the Kgotlelelang Basadi HBC Centre which is situated in Ngwanamago village in the Maja tribal authority in the Polokwane municipality, Limpopo. Ngwanamago village is about 30 kilometres south of Polokwane, the capital of Limpopo. The centre serves four rural villages, namely Ngwanamago, Thaba, Makata and Matobole, where unemployment and poverty is rife. Although there are similar centres in the nearby villages the study was limited to the Kgotlelelang Basadi HBC Centre, since it is unique in the fact that it is not engaged in any other projects, e.g food production for the patients, like other organisations or HBC centres. The

centre only focuses on health care. The researcher's objective was to explore the educational needs and assets of HBC-givers at the Kgotlelelang Basadi HBC Centre.

## **1.8 Ethical considerations**

Ethics is a set of moral principles which is suggested by an individual or group, is subsequently widely accepted, and which offers rules and behavioural expectation about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students (Strydom, 2011:113).

Punch (2009:109) states that before any person participate in a research study, the researcher must provide the prospective participant with a description of all features of the study that must reasonably influence his or her willingness to participate. According to Strydom (2011:117), when subjects are involved without their consent they may be unaware of their rights and will thus think that they are obliged to participate without the possibility of terminating their involvement as subjects. Strydom (2011:118) thus maintains that informed consent ensures the full knowledge and cooperation of subjects, while also resolving or at least relieving, any possible tension, aggression, resistance or insecurity in the subjects.

Before embarking on this research, the researcher obtained a letter of consent from the head of the Community and Continuing Education Unit at the University of Limpopo, which was handed to the manager of the Kgotlelelang Basadi HBC Centre. The purpose and significance of the study was explained to all participants before obtaining their written consent. They were briefed on their roles, and informed that participation would be voluntary. Punch (2009:109) advises that volunteers should always be assured that they may withdraw from the study and end their participation at any time.

Punch (2009:119) further explained confidentiality as an agreement between the researcher and the participants about what may be done with the information obtained from the participants. Privacy "refers to controlling other people's access to information about a person" (Punch, 2009:118). It means not revealing the identity of the participant to anyone other than the researcher and his or her staff. Therefore, the privacy of the participants is protected by ensuring anonymity and confidentiality

throughout the research process, and in cases of direct quotes, participants' names are concealed.

Nevertheless, the participants agreed to be photographed and their photos appear in the research report. They were further assured that data will be appropriately stored and maintained before, during and after the research process. A relationship of trust and respect with the participants was established and maintained throughout the research process. The researcher also endeavoured to set personal biases aside by returning transcriptions to the participants for verification of their responses.

Punch (2009:109) indicates that informed consent is about agreeing to participate in a study after being informed of its purpose, procedures, risks, benefits, alternative procedures and limits of confidentiality. Once the research ethics were explained to the participants, the researcher obtained the participants' - the caregivers, patients and the nurse - informed consent in written form: each participant signed a letter indicating her voluntary participation and rights.

## **1.9 Conclusion**

This chapter provided the background of the study. It highlighted the representation of the findings of other similar studies. The rationale for HBC in South Africa, and that of the neighbouring country, Botswana, was explained. The socio economic profile of the four villages was presented and summarised as that of poverty, unemployment and a low literacy level. The statement of the problem was outlined. The HBC-givers at Kgotlelelang Basadi HBC Centre, although offering essential services in the form of health care, seem to lack training and as such put patients and themselves, as well as others with whom they come in close contact, at risk of spreading contagious diseases.

The aim of the study, to explore the educational needs and assets of the HBC-givers, was presented together with the objectives and the research questions. It is clear that HBC is essential and that HBC-givers should be adequately trained in order to be effective in their work.

The next chapter presents the theoretical framework of the study.

## **CHAPTER TWO THEORETICAL FRAMEWORK**

### **2.1 Introduction**

This chapter presents the available information on HBC and the caregivers, adapted from other researchers. The different types of caregivers are the focus of this study. The different HBC models from South Africa are discussed. These models include the chronic care model; the service model which includes comprehensive HBC and home visiting models; the structural model which includes and are initiated and driven by isolated agencies such as collaborative and integrated, specialised or private hospitals, NGO, CBO, and Faith Based Organisations (FBO); and lastly the informal HBC setting model.

The researcher's assumptions on the educational needs and assets of HBC-givers is discussed and substantiated by the literature. These assumptions include, inter alia, adequate qualifications, relevant and adequate educational training programmes, administration and managerial experience, monitoring, support, and funds and resources.

The process on the assessment of needs and assets will be explained, cited from other researchers. The section will also include definitions of key concepts which are home-based care, caregivers, chronic illness, educational needs, educational assets, palliative care, volunteers, community-based care, the home-based care referral system and counselling.

### **2.2 Literature review**

HBC for People Living With HIV AIDS (PLWHA) in South Africa is shaped by the African culture of care-giving where many people take care of ailing family members (Mieh, Airhihenbuwa & Iwelunmor [Sa]:198). The issue of HBC in South Africa gained momentum after the tremendous spread of HIV/AIDS, hence the HCBC guidelines of 2001 by the DoH, since all home-bound patients deserve to be cared for at home.

Usinga (2012:15) states that HBC has a number of advantages that include, inter alia, early identification and referral of PLWHA, reduction in hospital expenses, overcrowding of hospitals, sharing of health care resources and complementing existing health services. HBC is beneficial to the DoH since patients would be discharged to the care of HBC-givers at the patients' homes, thus relieving hospitals from the burden of overcrowding. Moving from house to house can also assist in locating people who are ill but not on treatment, who can then be referred to a clinic or hospital for further diagnosis.

HBC may contribute to quality care of people who suffer from various chronic conditions, including HIV/AIDS, as well as the disabled, the elderly and vulnerable children. HBC furthermore promotes the principle of Ubuntu where the people in the communities care for each other (Friedman, Mothibe, Ogunmefun & Mbatha, 2010:4). HBC is not new to the the communities in the South African provinces of Limpopo, KwaZulu-Natal, Eastern Cape, and Gauteng: although it was not formalised, people have been taking care of ill family members. Traditionally women were charged with the care of the ill, disabled or elderly for they were often home while the men went out to work.

Care for home-bound chronic patients is provided by caregivers, usually volunteers. "A caregiver is someone who provides care" (Jooste, 2008:33), however, Mabusela (2010:23) states that different authors and institutions (pending on where the caring services are being offered) use different names to define the caregivers. Names such as carers, caregivers, community caregivers, health workers and HBC-givers are used.

There are two types of caregivers. The first refers to formal caregivers, which include professionals and specialists such as physicians, pharmacists, medical social workers, occupational and speech therapists, doctors and nurses (Mabusela, 2010:23). The above category also includes trained volunteers, spiritual counsellors associated with AIDS service organisations, and AIDS care teams and hospice programmes. The second type, the informal caregiver, provides care at home on an unpaid basis to relatives, spouses and friends (Mabusela 2010:23).

American people with disabilities need some form of home care assistance, 80% of that provided by informal or unpaid caregivers (Buchana, Radin, Chakravorty & Tyry,



(2010:12). The data was collected in a national survey of 530 informal caregivers. Another study in America by Families USA (2010:1) affirms that Home and Community Based Services are significant to senior people and people with disabilities for they are able to stay at home, unlike in institutions. HBC is beneficial to some patients in the sense that they enjoy the comfort of their homes surrounded by their families, friends and the whole community.

Campbell and Foulis (2004:10) conducted a study on the experiences of home-based care-givers in caring for people living with HIV/AIDS. Their study was conducted in Malawi using a qualitative research method. They found that caregivers do not have the necessary knowledge and as such they are unable to deliver effective care. Dippenaar, Chinula and Selaledi (2011:23) conducted a study in the Lilongwe district of Malawi and indicate that the HBC approach was adopted by the Malawi National HIV/AIDS policy as one of its major components. Many countries introduced HBC formally following the alarming high rate of HIV/AIDS infection.

According to Lindsey *et al* (2003:2), who conducted a study on home-based care in Botswana, using a qualitative research method, caregivers experience socio economic problems such as poverty, social isolation, stigma, psychological distress and a lack of training in care giving. Apparently the Botswana government does not have clear policies in heeding HBC-givers, who are impoverished for they do not receive salaries. Lack of training and stigmatisation may also lead to negative feelings related to their role of care giving.

In their Lesotho study, Makoae and Jubber (2008:36) found that HBC-givers deliver care effectively if they are supported by hospitals. Monitoring and support of caregivers is essential for it acts as motivation. They also established that most caregivers in Lesotho are family members who sometimes only become familiar with the illness at a later stage, bearing the fact that HIV/AIDS related illnesses are usually managed in secrecy because of fear of stigmatisation, and thus make it difficult for those caregivers to offer care in the most effective way.

The study completed by Lund (2010:506) in South Africa revealed that HBC-givers work at private homes, usually in poor communities, and as such they are “invisible” and are not adequately remunerated. It was also established that some of them do this

work, even without remuneration, for they believe that the experience acquired in HBC will enable them to obtain better jobs. Apparently HBC-givers are not well organised to air their complaints to the government, while the government in turn seem not to recognise the value of HBC-givers and thus exploit them.

Akintola [Sa] conducted a research study among volunteers in the Amanzimtoti-Durban area using a qualitative research method, and found that volunteers received training which enables them to provide basic nursing assistance to the patients. This basic nursing assistance include inter alia, pressure-, wound-, skin- and mouth care infection control, and guidance and support for adequate nutrition. Nemathaga (2008:140) states that home or community-based caregivers who receive comprehensive and continuous training would be able to sustain caring activities efficiently and with confidence.

Sobuce (2007) conducted research on the experience of home-based caregivers at Lusikisiki in the Eastern Cape, using a qualitative research method, and found that one of the roles of the caregivers is to hand out tablets. However, sometimes they administer medication to patients intended for their personal use, but coincidentally the patient improved to such an extent that, when the patient experiences pain, he or she would ask for the same tablets again. Sobuce (2007:33) further indicates that treatment intended for another disease or for another person is often used for someone else. In the researcher's view this is proof that the carers experience problems, bearing the fact that they administer medication not prescribed by a doctor or a nurse. Caregivers should be supervised in their patient treatment to ensure that they adhere to treatment instructions, not to administer medication which is not prescribed by doctors or nurses, for that could put patients' health at risk (Sobuce, 2007:35).

Van Graan, Van der Walt and Watson (2009:309) completed a study in Potchefstroom in the North West Province, South Africa, using both quantitative and qualitative data collection, and established that non-professional caregivers experience personal problems with regard to available resources, the extent of their knowledge of caregiving, lack of training and psychological impact. Lack of adequate training and resources may put both the caregivers and the patients at risk in the sense that the caregivers may not know how to handle patients suffering from certain diseases as well as how to use some resources, if any.

Maphula and Mudhovozi (2012) used a qualitative research method in their study and found that stigma and discrimination against the patients and lack of resources and training are the challenges faced by the caregivers in the Thulamela Municipality, Limpopo. Patients are afraid of being discriminated against due to their condition and the perception of it, and thus may be uncomfortable when caregivers visit them at home. Furthermore, lack of training and resources may hinder the effective delivery of caring activities by HBC-givers.

Another study on home-based caregivers was completed by Jackson (2007) in the Capricorn region of Limpopo, using a qualitative research method. Her findings are that home-based caregivers' duties are to provide physical and emotional care and to perform household chores where needed. Caregivers also train family members on the care of their patients. Jackson (2007:74) recommended that caregivers should be appropriately trained and should receive support from relevant stakeholders. However, she also indicates that termination of service by caregivers, who received the available albeit inadequate training, impact on service delivery in the community. Trained caregivers sometimes resign from their caring work due to their dissatisfaction with their service conditions.

Ncama (2005:33) notes that the HIV/AIDS epidemic has placed a large burden on public health facilities in developing countries which already function with limited resources. She indicates that most countries shifted the burden of care from hospitals to the families and community HBC.

According to Lund (2010:499) the term HBC covers the existing types of community-based health workers who have emerged in response to the growing need for care associated with HIV/AIDS. However, home and community care is not only meant for people living with HIV/AIDS, but also for chronic patients suffering from different diseases, as well as the elderly, people with moderate to severe functional disabilities, mental illness and the primary caregivers of those people.

Akintola (2004) conducted a comparative research study in South Africa and Uganda, and revealed that HBC programmes in South Africa are inadequately developed compared to those in Uganda. Akintola (2004:3) furthermore highlights that many HBC programmes and projects in South Africa experience managerial problems and are

therefore unsustainable. In South Africa these programmes rely on volunteers from the affected communities who are usually unpaid or receive a small stipend. The fact that HBC-givers, without relevant qualifications or appropriate training, volunteer their services may result in the lack of managerial skills which would hamper the progress and sustainability of an HBC organisation.

Apparently the South African government does not monitor or fund HBC programmes to ensure proper management and sustainability. Akintola (2004:3) states that HBC programmes in Uganda is professionalised, for patients at home are provided with specialised medical care and support, since teams of medical doctors, nurses, paramedics and clerics for spiritual care pay home visits. According to Akintola's findings one may conclude that the HBC programmes in South Africa need a lot of planning and management as well as monitoring and support by the government and other stakeholders.

The present study differs from the above studies since it is based on the educational needs and assets of home-based caregivers for home-bound chronic patients. However, there are various types of HBC models in South Africa, differing in the type of care they offer. Some of these models, like hospices, employ caregivers and pay them salaries rather than recruiting volunteers.

## **2.3 Home-based care model**

### **2.3.1 Home-based chronic care model**

WHO (2003:10) refers to the caring of chronic illness and disability as "tertiary prevention" since it includes rehabilitation and palliative- and long term care. According to Singh and Ham (2006:5) the chronic care model links knowledgeable and active people with patients suffering from long term conditions.

The home-based chronic care model (HBCCM) was designed to address the needs of patients with chronic diseases, and also facilitates the design of chronic care delivery within the home health sector by ensuring patient-centred evidence-based care (Suter, Hennessey, Florez & Suter 2011:43). Home-bound chronic patients may benefit from this model since it is designed to cater for patients who suffer from various chronic conditions.

### **2.3.2 Service models**

- ***Comprehensive home-based care***

Ncama (2005:36) states that comprehensive HBC provides palliative care and is run by established Non-Governmental Organisations (NGOs), such as the Hospice Association of South Africa, Red Cross Society, and churches. In the comprehensive HBC model caregivers are trained to offer services such as counselling, cleaning and dressing of wounds, oral hygiene, supervision of medication use and administration, necrotic wound care, pain management and diagnosis of opportunistic infections as well as a directly observed treatment short course (DOTS) for tuberculosis (Ncama 2005:36). Ncama (2005:36) further indicates that some comprehensive HBC programmes incorporate orphan care, social support and income generating activities, voluntary counselling and testing services, health education, primary and secondary prevention activities, and de-stigmatisation. Ncama is supported by Lo lacono and Allen (2011:16) who state that cooperatives in HBC are involved in income generating activities to enhance the living conditions of their affected and infected members. Services such as wound care, diagnosis of opportunistic infections, DOTS voluntary counselling and testing and health education, need to be performed by people who received comprehensive training and are literate in order to provide written feedback, e.g writing reports.

WHO (2004:2) states that in the South East Asian Region, the comprehensive community home-based Health Care model places patients at the centre of care and acknowledges that individuals, groups and communities contribute in achieving and monitoring their health and managing illness throughout their life-spans. In the researcher's view, patients are the main reason leading to the establishment of HBC organisations and as such the main focus should be on the patients via the involvement of all stakeholders.

WHO (2004:6) asserts some strategies for involving stakeholders in comprehensive community home-based health care (CCHBHC). Stakeholders who should be involved include families, communities, village committees, religious groups, individuals, NGOs, referral organisations, volunteers, agencies, self-help groups and all existing local structures. All the above mentioned stakeholders could work together in improving and sustaining CCHBHC. According to WHO (2004:2) CCHBHC could be sustained if

stakeholders can engage in activities such as communication and decision making, organising community meetings, networking, and commitment.

- ***Home visits***

In this type of service model volunteers visit patients at their homes and spend time talking to and educating them and their families about basic care needs. Home visiting also provides support with cooking and cleaning, as well as accompanying patients to health facilities (Ncama 2005: 36). It is therefore important that volunteers should be educated, committed, motivated and influential in order to educate patients and their families. Some patients do not live with family members and thus, when they are very ill, cannot clean or cook and rely on volunteers for assistance.

### **2.3.3 Structural models**

- ***Isolated agencies***

Examples of isolated agencies include self-help projects among certain groups, like church groups and some NGOs. They are referred to as “isolated structures” for there is usually no formal referral system in place or integration into the already existing health care system (Ncama 2005:37).

Ncama (2005) is supported by Van Dyk (2008:334) who indicates that isolated agencies are based on a single service HBC model. She states that one service provider (usually a clinic, hospital, NGO or church) organises HBC by recruiting and training volunteers, and bring them into contact with patients and their families at home.

- ***Collaborative and integrated model***

According to Ncama (2005:37) this model comprises the collaboration between a number of partners and programmes which are often integrated into some health care service. Some work with volunteers, whereas others work with paid trained employees. Uys (2003:5) states that the integrated HBC model links all service providers with patients and their families in a continuum of care where patient and family are supported by a network of services, such as community caregivers, clinics, hospitals, support groups, NGOs and community-based organisations (CBOs) as well

as the larger community. Uys (2003:6) further indicates that the integrated model allows referral between all partners and also ensures that community caregivers are trained, supported and supervised.

South Africa has an integrated community based care (CBC) programme (DoH 2002:9). In their study conducted in the Vhembe District in Limpopo, Morwe and Ramaila (2012:229) state that the integrated HBC model links all service providers with patients and their families in a continuum of care. They further indicate that this model builds trust and enhances referrals between partners and, most importantly, the caregivers receive training, support and supervision.

- ***Specialised / private model***

According to Ncama (2005:37) the specialised / private model is practiced by developed countries where specialists, such as physicians linked to hospitals, take care of PLWHA at home. This model, however, is expensive. In South Africa the specialised / private model is practiced by individuals who can afford to pay for health services offered at home by specialists.

- ***Hospital initiated and driven model***

Hospitals are in charge of this type of HBC model for their own benefit. This kind of programme is delivered by hospital teams or individuals based at hospitals, where volunteers are recruited and trained by hospital teams (Ncama 2005:37).

- ***Non-governmental organisation, community-based organisation and faith based organisation initiated and driven model***

In this model employees receive training (Ncama 2005:37), as opposed to volunteers who receive no or little training. An example of this model is the Hospice Association of South Africa and the Red Cross. Such organisations are formally organised and caregivers receive training, thus enabling them to offer quality service to patients.

### **2.3.4 Informal home-based care setting model**

According to Uys (2003:7) in this model, families care for their own at home with the informal assistance of their own social network. This model has been practiced for many years by family members who lack the necessary knowledge and skills; caregivers rely on their life skills, and supervision of care is often unavailable.

According to the researcher, the collaborative and integrated HBC model can be employed for home-bound chronic patients since it involves stakeholders in health systems, NGOs, and communities, as well as patients and their families and also allows for referrals. One of the goals and objectives of HBC is to ensure access to care and follow-up through a functional referral system which is applicable in the collaborative and integrated HBC model (DoH 2001:8). Kgotlelelang Basadi HBC Centre operates under the policies as stipulated by the South African DoH, hence the national guidelines of 2001.

In order to provide appropriate care and support for PLWHA, especially in less developed countries with minimal resources and health budgets, a comprehensive integrated approach which addresses the medical, psychological, spiritual and emotional needs is necessary where a number of stakeholders will collaborate to ensure quality care (Fox, Fawcett, Kelly and Ntlabati 2002:6).

HBC is the caring of patients who are home-bound and those who manage their conditions without being home-bound. However, all types of patients are being cared for by formal and informal HBC-givers. Most home-based caregivers are family members or volunteers who receive little or no training or support even though they perform their caring role in adverse conditions (Campbell and Foulis (2004:2). Friedman *et al* (2010), using qualitative and quantitative research methods, established that HBC organisations are concentrated in rural areas where their services are needed most. The majority of people in urban areas have easy access to care since they are surrounded by health care facilities and transport is always available, unlike rural areas where hospitals and clinics are far from the villages where transport is also limited. Furthermore, some people in urban areas can afford specialised care since they are employed. Friedman *et al* (2010:9) further state that a large number of HBC organisations are based in the rural areas of provinces, such as Limpopo and the Northern Cape.



The Kgotlalelang Basadi HBC Centre may be classified under the collaborative and integrated model since the organisation involves different stakeholders like the DoH, DSD, clinic, community, and other CBOs. Some models do not offer services to home-bound chronic patients; instead their patients are institutionalised at places like hospices which are often privately owned. In the collaborative and integrated model service providers are linked to patients and their families as primary caregivers. However, caregivers in all models should possess skills and knowledge in rendering care services. In order to ensure continuous and quality care of patients, the educational needs and assets of HBC-givers in all models need to be explored and identified.

## **2.4 Assumptions**

The researcher assumes that home-based caregivers do not have adequate qualifications, have access to relevant or adequate training programmes, administration and managerial experience, monitoring and support as well as funds and resources. These assumptions are explained at the hand of literature.

### **2.4.1 Adequate Qualifications**

Seemingly HBC-givers do not have adequate or relevant qualifications for the health care services they offer. The South African DoH (2002:15) maintains that the educational standard of caregivers is generally low and is viewed by some as a limitation towards the training process. It is further stated that in Eseleni, Kwazulu-Natal, the average education of care-givers is Grade 3; many who were trained by the Zululand Hospice Association could not read or write, and could only speak Zulu (DoH 2002:15). These caregivers will not be able to offer appropriate care for patients, due to the fact that they cannot read or write reports, prescriptions and referrals. It is difficult for caregivers with a low literacy level to read and understand training manuals, instructions on administering medicine or to interpret apparatus readings from e.g thermometers or sphygmomanometers or sign an attendance register.

According to Nzimakwe and Xaba (2008:133) South Africa started educating and training caregivers in the 20<sup>th</sup> century since their standard of education was questionable. However, some of the trainers were health personnel whose

qualifications were not specified while some had no certificates. It is evident that HBC in South Africa is not seriously taken as an essential health care service provider, for the trainers are often unqualified. Lack of quality training will thus lead to HBC-givers acquiring irrelevant and inappropriate information and/or qualifications.

Every organisation considers relevant qualifications when selecting employees to ensure effective and quality service, but it seems that this principle doesn't apply to HBC-givers, for relevant qualifications and literacy level are not taken into consideration in their selection or employment. According to the South African DSD (2012:47) selection criteria for CHBC-givers include, among others, people who are 18 years or above; they must be South African citizens with no criminal record; have no permanent job; must be mentally stable and trustworthy; and should be able to uphold principles of confidentiality and have the same values as the community they serve. The DSD (2012) further states that people who stand for HBC selection should be willing to fight against HIV/AIDS and other chronic conditions.

According to the above statement, qualifications and literacy level is not considered as important requirements. However, looking at the services offered by CHBC-givers listed in the same document (DSD 2012:20), most of the services need some sort of qualification regarding knowledge as well as basic reading and writing skills in order to be able to read training manuals and write reports.

Contrary to the DSD (2012), the DoH (2002:14) confirms that in terms of hospices the criteria used to select HBC-givers includes, among others, good communication skills, previous training on counselling and an appropriate level of literacy.

Gardiner (2008) believes that previously there were no opportunities to learn literacy skills. Furthermore, there was no need for people in rural areas to attend school which resulted in many South Africans still lacking basic literacy skills. Gardiner further stated that, in parts of Limpopo 23% of women had received no formal schooling at all, 19% had left school before completing Grade 7 and 16% had discontinued schooling after completion of Grade 7. It shows that most women in Limpopo are illiterate. Moreover, it is believed that most HBC-givers are women, which implies that HBC is mostly offered by illiterate women. This is supported by the findings of several researchers, among others Kang'ethe (2009) and Akintola (2006), who agree that CHBC pro-

grammes are gender based and mainly offered by older women who are usually impoverished.

Kang'ethe's (2010:550) research in Gaborone, the capital of Botswana, established that most women have never attended school. Caregivers indicated that their low literacy level was to be blamed for their low coping capabilities and low quality care. It is also indicated that a low literacy level is a source of stress since those who are illiterate could not easily understand the complications of care-giving. Kang'ethe (2011:470) reiterates that a low literacy level impedes the caring of PLWHA. Morwe and Ramaila (2012:232) maintain that low literate caregivers are unable to access care-giving education or disease progression or follow medical and hygiene protocols. Illiterate people are not able to access any professional education since it requires writing and reading skills and understanding technical language and training manuals. Contrary to the above studies, Mabusela (2010:59), in a study conducted in Mamelodi in Gauteng, revealed that 90% of the caregivers passed Grade 12 and 10% left school in Grade 11. This would mean that most of the caregivers in Mamelodi should be able to perform their caring activities effectively since they are able to access the necessary care giving education.

It is mainly women who are involved in HBC programmes for most of them are unemployed and have little to do at home. People volunteer their services, lacking any qualifications, hoping for reward or because they are unemployed (Akintola [Sa]:10). However, Akintola ([Sa]:12) also indicates that some people show up for recruitment interviews but quit even before training starts for they cannot work without remuneration or cannot cope with the nature of volunteer work.

Volunteers render an essential service and therefore need to be appropriately trained and supervised by health workers (WHO 2003). Although they are non-formal – usually untrained – caregivers, they are essential to the Health system, and it would be advantageous if they could produce some evidence of education and experience to show that they are capable of executing their caring duties effectively. WHO (2003) is supported by Mohammad and Gikonyo (2005:13) who note that volunteers are essential to the sustainability of HBC. If volunteers are essential service providers, they need to be educated and possess relevant qualifications since they deal with the lives of people.

The National HBC Programme and Service Guidelines in Kenya (2002:24) states that community health workers should be able to read and write well enough to use reference materials and write reports. According to Wouters, Barjis, Maponya, Martiz, and Mashiri (2009:1) inadequate literacy is one of the greatest challenges facing the development of rural areas in South Africa. Many rural people still lack basic literacy skills. The present researcher is of the opinion that HBC-givers should be literate enough to be able to write reports, referral letters, minutes, and help patients in reading the dosage, indications, warnings, side effects and special precautions of medication.

Apparently there is no screening or interviews for HBC jobs: without adequate qualifications the caregivers will not be able to understand the dosage of medication they have to administer to the patients. There are also some apparatuses and resources to be used in caring for home-bound patients which need expertise. However, Mabusela (2010:58) confirms that HBC-givers in Mamelodi undergo vocational training on HBC provided by the centre, which is a prerequisite to do the caring work. Before caregivers could resume their caring duties, an extensive training should be offered to equip them with the necessary skills.

Friedman *et al* (2010:47) state that electronic reporting on HBC activities and finances to their funders and the DoH can save time and space as they will no longer need to print and file information. Friedman *et al* (2010:12) also recommend that all HBC organisations that have received computer equipment should be trained by government or appointed agents, since this will improve the quality of their services and reports. Training in the use of electronic devices would be appropriate for HBC-givers and improve the quality of care to patients, while it would be nearly impossible to train illiterate caregivers to use equipment such as computers. Therefore, lack of education will impede their development.

Akintola ([Sa]:21) established that at Sinosizo HBC in KwaZulu-Natal caregivers are concerned about their low level of education and believe that assistance to further their education would enhance their effectiveness and efficiency in their caring capacity. Jooste, Chabeli and Springer (2010:5) conducted their study in the northern suburbs of Johannesburg and found that some patients' conditions worsen due to incorrect administration of medication. This might be due to inadequate education and training.

Van Graan *et al* (2009:310) revealed that caregivers in Potchefstroom have insufficient knowledge in several important areas of care. They recommend a training programme for the caregivers and that, upon completion, they should be awarded certificates stating competence as community-based caregivers to enhance motivation. These certificates should be fully accredited with a Sector Education and Training Authority (SETA) like Health and Welfare SETA (HWSETA) and Education and Training SETA with the South African Qualification Authority (SAQA) qualifications. These certificates will serve as proof of qualification hence it will be evident that the caregiver is equipped with the necessary knowledge.

Morwe and Ramaila (2012:232), who conducted a qualitative study in the Vhembe District in Limpopo, established that lacking formal education not only prevents caregivers from accessing gainful employment in the labour market, it also compromises the quality of care offered to their patients. Low literate caregivers are unable to access care giving education, including assessing disease progression and following medical and hygiene protocols.

According to the Networking HIV/AIDS Community of South Africa (NACOSA) (2013) the HBC policy is not clear about the future of HBC education. NACOSA also states that appropriate qualifications for Community Health Workers (CHW) have been established but as for the HBC-givers there is no clarity on such. However, HBC-givers are involved in a deeper and more intensive level of home care of individual community members (NACOSA 2013). The researcher is of the opinion that HBC-givers offer essential services, like any other health worker, and as such should possess some relevant qualifications, bearing the fact that they deal with critical issues in caring for chronic patients of whom some do not have the knowledge and information on caring and managing their conditions, let alone taking their medication properly.

Morwe and Ramaila (2012:232) recommend that the South African government should collaborate with higher education institutions and provide accredited training to caregivers which will lead to the latter acquiring qualifications. The aforementioned researchers further stated that, should the HBC field be professionalised, HBC-givers will be permanently employed and enjoy employment benefits like medical aid, housing allowance, pension and labour law protection which will thus serve as motivation.

The work of HBC-givers continues to be unnoticed and is hardly rewarded, leaving carers to suffer physically and mentally (NACOSA, 2013). In addition, NACOSA (2013) highlights key issues regarding caregivers' professional status that need urgent attention. Key issues include recognition, respect, fair condition of employment, training and professional development. The researcher's view is that HBC-givers should be professionally recognised, and their scope of employment should be clearly defined with a standard salary and acceptable conditions of service as stated in the labour law policies. This would result in effective quality care of patients at their homes.

#### **2.4.2 Relevant and adequate educational training programmes**

Home-based caregivers do not receive relevant or adequate training to provide care to home-bound chronic patients. The researcher states that HBC-givers need to be well trained to acquire knowledge and skills on different chronic diseases. Further-more, they should be equipped with skills such as communication and counselling, community organisation, and general caring, including patient assessment and medication as well as home visiting skills.

Nzimakwe and Xaba (2008:133) state that education and training of health care workers or caregivers started in the 20<sup>th</sup> century in South Africa. However, there is currently no syllabus approved for training and education of health care workers. Although training was started, findings of other researchers indicate that most HBC-givers are not trained or rather inadequately trained.

Mohammad and Gikonyo (2005:13) indicate that human resources are the key challenge faced by CHBC programs which require immediate attention in the areas of training, capacity building and technical expertise. They further state that CHBC providers are inadequately trained and are too few to effectively carry out the necessary caring activities and services. To relieve the current situation, they suggest a nationally recognised training programme for HBC-givers. Apparently there is an insufficient number of adequately trained personnel across the board of CHBC programs (Mohammad and Gikonyo 2005:9).

Staff in the CCHBHC model needs to be equipped with knowledge, skills and attitudes to work in the community and other sectors as well as to train and support volunteers and other non-formal caregivers in addition to their clinical skills (WHO, 2003:25). WHO (2003:25) further states that in order to ensure competency in answering the needs, training should be provided systematically and continuously. Continuous training and development is vital for HBC-givers since science and medical research constantly develop new treatments and medication for different diseases.

According to Jack, Jenkins and Eslin's (2010:17) findings of their study conducted at Eden in the central Karoo in South Africa, home-based caregivers attend a basic five day course (40 hours) or the advanced course over 3-4 weeks (120 hours). The authors are of the opinion that this training period is not enough, especially since they are dealing with people's lives. Caregivers need to be well informed to perform their services competently. Training needs to cover a wide scope in as far as caring, counselling, medication, report writing, and record keeping are concerned.

The study conducted by Lindsey *et al* (2003:487) in Botswana reported a lack of basic care-giving education among HBC-givers. Kang'ethe (2009:27) also established that caregivers in Botswana either have never been to school or had only primary level education. Illiteracy was found to contribute to a low level of care, low productivity and poverty (Kang'ethe 2009:27), while illiterate HBC-givers may not be effectively trained.

The above studies indicate that many HBC-givers do not receive adequate training. The low literacy level may be an obstacle in enabling caregivers to be trainable since they will not be able to read the training manuals. The researcher agrees that caregivers should receive intensive training, for it is clear that a low literacy level will impede their understanding and affect the quality of care patients receive.

Akintola ([Sa]:7) notes that caregivers should provide their patients and their families with information about HIV/AIDS and tuberculosis (TB) transmission and prevention, alcohol abuse, nutrition and positive living, available resources in the community and assist in preparing their documents for social welfare grants. This definitely calls for literate and well-trained volunteer caregivers who can effectively perform their HBC duties. However, contrary to the above mentioned studies, Akintola ([Sa]:7) indicates that volunteers receive training which enable them to provide basic nursing assistance

to patients. These include pressure-, wound-, skin- and mouth care, massaging, infection control, and guidance and support for adequate nutrition. Well-trained volunteers are thus able to offer an informed health education to patients and the community at large.

Lack of training may lead to HBC-givers being infected for they may not have relevant information on different diseases and how to safely handle such patients without themselves becoming infected. HBC-givers' training on HIV/AIDS palliative care is inadequate, and this put them at risk of being infected with HIV (Morwe and Ramaila 2012:228).

Volunteer caregivers regularly assess patients to monitor their rate of recovery. Akintola [Sa]:8) notes that patients are sent to the clinic or hospital after assessment by volunteers. Supporting Akintola ([Sa]), Mieh *et al* ([Sa]:193) asserts that HBC-givers acquired knowledge through training and their daily interaction with patients, hence they are able to provide information to and counsel PLWHA. Training, education and experience acquired throughout the caring process can equip volunteers with skills and information with regard to assessing and monitoring the recovery of patients.

Akintola ([Sa]:12) further indicates that some volunteer caregivers receive training on HBC and then proceed to use the knowledge and skills acquired for themselves or members of their families without joining the volunteer programme. This indicates that volunteer caregivers are trained in other localities besides Amanzimtoti.

Nevertheless, in the aforementioned study it was revealed that the need for personal development was a common issue raised by volunteer caregivers. One of the areas in which they believe assistance should be granted, is their education. Many of them, as noted, have a low-level education. This is supported by NACOSA (2013) which states that HBC-givers work for organisations that have their own funding problems, and as such have little job security or professional development opportunities.

Akintola ([Sa]) and NACOSA (2013) outline some of the HBC-givers' duties as to offer a package of care to terminally ill and elderly people, those living with HIV/AIDS, TB and people with chronic diseases like hypertension and diabetes. HBC-givers should also conduct community household and individual health assessment, identify health



needs and communicate information to families or individuals on how to access appropriate health services. Patients should be referred to clinics and hospitals for further assessment and testing after performing basic screening tests. Caregivers should further provide basic first aid and psycho-social support to patients.

In the researcher's view, only adequate and relevant educational training would allow caregivers to perform all the above mentioned duties effectively. Jooste *et al* (2010:1) in their study conducted in the northern suburbs of Johannesburg, suggest that the curricula of recognised training programmes should address the health care needs of home-based patients. However, they further state that formal recognition of Ancillary Health Care Workers' (AHCWs) training in HBC currently does not exist in South Africa, even though there are policies and documents that make provision for it.

WHO (2002), in concurrence with the latter researchers, indicates that an HBC worker requires adequate education and training, and that the content of the HBC curriculum should include among others, basic information on HIV/AIDS transmission and how to prevent it, managing referrals, resources, symptoms and administering medication. Furthermore, caregivers should offer counselling to terminally ill patients and the bereaved family. A curriculum which includes the above mentioned content will be relevant to the caring services that HBC-givers have to offer.

Jack *et al* (2010:533) found that one of the challenges faced by HBC-givers at Eden and the Central Karoo is the lack of effective training. HBC-givers should be offered an opportunity to be trained and educated on the relevant content related to their caring duties.

Van Graan *et al* (2007:310), in their quantitative single survey study in Potchefstroom, established that a small number of non-professional caregivers had received home care/healthcare training. It is suggested that an adequate and relevant training programme would assist in empowering non-professional caregivers to provide better health information to the community. This will strengthen and correct homecare skills which are based on life skills. In addition, the caregivers will gain essential skills and the ability to function as part of the community healthcare team, especially to deliver sustained, comprehensive community-based healthcare to children with HIV (Van Graan *et al* 2007:311).

Muwaniki (2010:20) points out that home-based caregivers need information on basic facts regarding HIV/AIDS since new developments on this pandemic is continuous. The researcher agrees with Muwaniki that HBC-givers should receive continuous training owing to the fact that there are many new developments emerging from research and intervention as well as advanced technology. For example, tele-monitoring includes the collection of clinical data and its transmission between patients at a distant location and a health care provider via electronic information processing technologies (Wouters *et al* 2009:3).

According to Friedman *et al* (2010:47) 1 275 CHBC organisations in South Africa reported that they have computer equipment but do not have computer literate staff. HBC-givers should thus be trained in accordance with the rapidly developing technology like using on-line services and internet.

Supporting the above mentioned researchers, Usinga (2012:30) established that the majority of ex-volunteers indicated that they strained to perform their duties properly and had to quit due to lack of adequate training in handling the challenges involved. The serving volunteers too indicated that they find their work difficult due to the same reasons mentioned above. Usinga (2012:30) states the need for an effective induction programme for recruited volunteers. New volunteers, lacking knowledge and experience, should be trained before they resume the duty of caring for patients, for deficient knowledge would put both volunteers and patients in danger of infecting each other.

If HBC-givers could receive education, support and continuous training from formally trained health workers, like nurses, they would be able to provide quality care with confidence (Mohammad & Gikonyo, 2005:4). HBC-givers, who are well informed on what is expected of them, will be highly motivated and perform their HBC duties effectively to the benefit of the patients, families and the community at large.

Hlophe (2006:2010) found, from a study conducted in the Free State that many HBC-givers are aware that their training is inadequate. Education and training is crucial in sustaining HBC activities. According to Guyer in the Huairou Commission (2008:3), HBC-givers with limited access to skills training may end up providing poor quality health care. Guyer (2008) is supported by Sobuce (2007:121) who asserts that

volunteers not adequately trained are of little help to patients, and therefore recommends that training should be compulsory for practising HBC-givers.

Cameron (2003:33) highlights that adequate training of caregivers is imperative for it will facilitate a high standard of HBC. Contrary to this, care-givers ill-equipped with the necessary knowledge and skills will not be able to function as part of a health care team, which could result in the HBC programme being unsuccessful. It is also strongly recommended that HBC volunteer training should comprise of theory and practice at a clinic or hospital where the level of care can be observed and evaluated (Cameron, 2003:36). However, caregivers who are illiterate may not cope with the theoretical part of training.

### **2.4.3 Administrative and managerial experience**

The quality and competency of every organisation depends on good management. Management expertise by HBC-givers is essential for they are expected to manage their caring activities effectively. However, the majority of HBC-givers have no managerial or administrative knowledge. With no relevant training, they are unable to manage their time, adhere to patients' visiting schedules, keep records, and manage other activities of the organisation. A manager, secretary, coordinator and finance officer may be appointed from among the HBC-givers, whom the researcher assumes lack these required managerial and leadership skills.

Management should establish HBC policies for the functioning of the service and to prevent problems as far as possible (Uys 2003:9). The policies should include a job description and conditions of service for caregivers, a financial policy, a policy of confidentiality and disclosure, care policies - guidelines for dealing with specific symptoms - and a referrals policy between different service components. The management of an HBC organisation should be trained in implementing these policies, administering all the resources - including human resources - and activities of the organisation.

Mohammad and Gikonyo (2005:10) conducted research in Sub-Saharan African countries, using both qualitative and quantitative research methods, and found a lack of technical expertise in key areas of monitoring and evaluation and program management and implementation of activities and services in HBC programmes. The fact that HBC organisations do not have sufficient funds to employ qualified managers with

relevant experience result in the organisation employing HBC-givers as managers, coordinators and finance officers in spite of them not possessing those qualifications.

Both caregivers and their managers have to adhere to work ethics. Mabusela (2012:59) notes that HBC-givers meet every morning to clock in and then disperse to see their patients in their various sections and later return to sign out and report any challenges experienced during the day that need immediate attention. Wearing a uniform should make the HBC-givers distinctive and would probably prevent deviations. Poor management may result in caregivers not adhering to work ethics and other policies of the organisation.

According to Uys and Cameron (2003:126) each visit by the HBC-givers should be recorded together with developments regarding their patients. Records of prescriptions of each patient should be kept by both caregivers and the manager of the HBC centre. Patient records should be confidential and secure since it contain sensitive information which should be undisclosed (Uys and Cameron, 2003:126).

Proper records should be kept up-to-date to ensure smooth running of evaluation, monitoring and support processes to ensure continuity of care, which is also applicable to other participants in HBC. It is also necessary to keep good records of orders and delivery of supplies and equipment (Nemathaga, 2008:142, 144). Should records be kept poorly and the responsible person leaves, it would be difficult to achieve success or to continue where he or she has left.

An organisation which receives funding should have a budget and adequate management of those funds. HBC managers and supervisors are responsible for the administration of these, and the managers are required to provide statements to the funders (Nemathaga, 2008:145). Financial management knowledge and skills are needed in an HBC organisation where the management or finance officer will be able to compile the spread-sheet showing income and expenditure.

Communication in an organisation is essential; all agencies and community resources involved in HBC should communicate with one another. Nemathaga (2008:144) indicates that regular meetings with stakeholders should communicate the plans, developments, achievements, challenges and solutions thereof. Nemathaga (2008:

143) further notes that networking meetings are encouraged between different practitioners, organisations and agencies involved in caring for clients and families at home to ensure that care in the community is coordinated.

#### **2.4.4 Monitoring and support**

Monitoring is an on-going process of reviewing planned activities to ensure they are carried out in such a way that the goals and objectives of the organisation are met (Nduba & Van Acker Hebert, 2005:39). Monitoring and support is adjunct to evaluation. An organisation's activities have to be continuously evaluated to ensure effective monitoring and support: one aspect cannot be separated from the other. Once monitoring and evaluation is done, the necessary support should be provided on a continuous basis to assure that HBC-givers are always on track and well informed on new developments in health care.

According to Nduba and Van Acker Hebert (2005:40) "evaluation is the process of assessing actual progress towards a goal and the impact of programmes on target groups." Monitoring and evaluation help in identifying problems and provide possible solutions. The everyday activities of the HBC organisation, together with the caregivers' ability to carry out HBC duties, have to be evaluated and monitored to ensure effective quality services. Evaluation, monitoring and support can either be internal or external. Nduba and Van Acker Hebert (2005:42) indicate that management and staff can monitor and evaluate themselves, whereby they will be able to assess their performance and develop corrective measures.

Apparently home-based caregiver activities are not monitored, and also do not receive the necessary support from the relevant stakeholders. Being unmonitored they are likely to make mistakes and even neglect their duties. Support of caregivers is essential (Jack *et al*, 2010:533). Maphula and Mudhovozi (2012:145) concur with Jack *et al* (2010) that home-based caregivers need physical, material, and emotional support, which can be offered by professionals through supervision.

A lack of support for home-based caregivers' work thwarts their full dedication (Guyer, 2008:3). Once trained, they should be monitored and supported by both the department responsible for HBC as well as the stakeholders to establish progress and detect

problems that might be hampering progress and to identify weaknesses. Informal caregivers should be supported by recognising their contribution towards caring of patients and provide them with knowledge, skills, resources and emotional support to motivate and encourage them to continue their good work of caring for patients at home (WHO, 2003:4).

Monitoring is a tool which can help in the development and success of every organisation. Hlophe (2006:195) points out that on-going monitoring and evaluation can result in addressing changes and deviations. Hlahane (2008:127) indicates that activities and operations of an organisation may be unnoticed if the project is not well monitored by them or their stakeholders; the identification of successes, needs and challenges depend on this.

WHO (2003:14) maintains that health volunteers provide an essential service and therefore need to be appropriately trained and supervised by professional health workers. According to Mabusela (2010:39) an organisation which does not receive support from organisers and programme implementers is doomed to fail. An organisation can only be sustained if monitoring and support is offered.

Kang'ethe (2009:28) conducted research at Kanye in Botswana, using a qualitative approach and found that caregivers lack sufficient emotional and financial support from their families, neighbours, private individuals, traditional and political leaders, and other service delivery networks like NGOs and CBOs, and the community at large. Due to this lack of support these caregivers suffer psychologically from being neglected and abandoned to do care-giving with little or no assistance. Support is absolutely essential in every organisation for the implementers to be physically, emotionally and psychologically fit to do their caring work accordingly.

Monitoring and support is needed to establish whether the aims and objectives of an organisation are being achieved. WHO (2004:15) states that monitoring mechanisms need to be in place to ensure that activities are carried out according to plan, and, should any deviations occur, corrective measures can be taken immediately. In the absence of support and lack of recognition by the government, HBCs in South Africa find it very difficult to carry out their daily duties (Mieh *et al*, [Sa]:195). Caregivers are volunteers who need support because they often don't have sufficient knowledge on

what they are supposed to do. Continuous support will empower them to perform their HBC duties with confidence, knowing that they are doing things correctly, as required. Caregivers require support from especially health professionals, e.g professionally trained nurses, due to their limited skills and training so as to provide quality care (Jackson 2007:5).

According to Mohammad and Gikonyo (2005:7) CHBC programs cannot succeed unless they receive active support and participation from government NGOs and communities. Lack of personnel such as social workers, district HIV/AIDS coordinators and other stakeholders in CHBC programmes attest to poor coordination (Friedman *et al*, 2010:70). Jackson (2007:23) maintains that support can be provided in the form of clear policy guidelines, standards and regulations to govern HBC-givers. Some HBC organisations do not have clear policies and guidelines, and caregivers are often not conversant with their job descriptions.

Usinga (2012:16) indicates that it is necessary for people who are involved in community work to have access to personal and expert support. HBC-givers need psychological and emotional support from health professionals, for they may often face heart breaking situations like watching their patients dying. Some caregivers are stigmatised owing to the fact that they work with PLWHA (Usinga 2012:31) and therefore need counselling services.

The South African DSD (2012:34) confirms that community caregivers work under stressful conditions which lead to disillusionment and burnout. DSD (2012:34) further indicates that caregivers need support to do their jobs well, remain infection free and avoid burnout to ensure that the sustainability and quality of their services are not compromised. Support ensures that service providers remain on the right track. Lo lacono and Allen (2011:7) indicate that the key problems facing HBC service delivery are associated with a lack of links to formal social services like the DoH, DSD and health care professionals. However, Mieh *et al*, ([Sa]:198) concur with Lo lacono and Allen (2011) that care organisations receive very limited support from the government and NGOs.

HBC serves as a strategy to address HIV/AIDS but receive little attention or support from the growing global AIDS infrastructure (Guyer, 2008:3). The commission further

indicates that there is little documentation concerning the process of establishing, sustaining and evaluating HBC programs. Lack of monitoring and support to HBC-givers may prevent them from being dedicated to their work, and it may further undermine their work since they might be perceived as unprofessional.

Systematic supervision should provide support and develop caregivers (WHO, 2004:26). In addition, WHO (2004:26) further states that the supervision process provides a formal opportunity to acknowledge achievements and developments as well as to address obstacles encountered in the delivery of CHBC. Monitoring and support help to identify challenges and produce strategies to overcome those challenges. The needs and assets of an organisation can also be identified and help in planning where necessary.

An HBC organisation may not be successfully operational without evaluation, monitoring or supervision and support by both the implementers and the governmental institution personnel. The care-giving job is emotionally and physically demanding and as such the support of caregivers is essential. The level of monitoring and support, both internally and externally, at Kgotlelelang Basadi HBC Centre need to be examined to establish educational needs of the organisation.

#### **2.4.5 Funds and Resources**

It seems most home-based caregivers do not have funds or relevant resources, a fact that can hamper their work. According to Muwaniki (2010:16) home-based care organisations receive funding and technical support mainly from international non-governmental organisations and development. Many programmes throughout the world do not survive due to inadequate or a shortage of funds, even though they flourished at first; every organisation needs funds and resources to operate effectively. A shortage of funds and resources leads to failure of any organisation, including HBC programmes, even though they offer recognised essential services to the community. However, should an HBC organisation have sufficient resources but lack well trained caregivers to utilise those resources, then those resources will have no impact.



Available funds and relevant, necessary resources can motivate caregivers. If HBC organisations operate without funds, stipends for caregivers may also be a major problem and may lead to termination of their service.

- **Funding**

In the National Audit of HBC in South Africa, Friedman *et al* (2010:62) revealed that a major challenge in the North West province is the lack of funding. They also found that most HBC organisations in the Mopani district in Limpopo experience problems in as far as the caregivers' stipends are concerned (Friedman *et al*, 2010:63). Small or no stipends will demotivate HBC-givers and lead to gradual withdrawal from HBC, for they actually need to earn a living.

Lund (2010:500) points out that it is uncertain whether volunteers in HBC organisations are paid, and if they are paid, the amount is not known. Although the work of volunteer caregivers is promoted by the government, their employment status is unclear (Lund, 2010:500). Seemingly the government does not want to permanently employ caregivers where they will earn a salary and also be entitled to benefits such as pension, housing subsidies, and medical aid.

Community Based Organisations (CBOs) cannot access funding by themselves. They mainly depend on funding from the DoH and DSD (Friedman *et al*, 2010:63). Some HBC organisations have resources such as computers, but cannot use them since they cannot pay electricity bills due to lack of funds (Friedman *et al*, 2010:48). In other countries primary sources of funding may be international or national donor agencies, NGOs and FBOs (WHO, 2002:19). Apparently, HBC programmes seem to lack stable funding organisations or governmental sectors. Programmes mainly rely on donors, a fact that may result in HBC programmes being perceived as less authentic by both caregivers and the community.

According to Friedman *et al* (2010:44), Limpopo has the highest number of HBC organisations that are funded by the DoH and NGOs which amounts to 336. KwaZulu-Natal follows with 178, Gauteng with 168, and the Eastern Cape has 149 funded organisations. The Northern Cape had the least number of funded organisations. Friedman *et al* do not state whether the funds are sufficient and always available to sustain these organisations.

Browning (2008) conducted research in Botswana at three HBC organisations, namely Holy Cross Hospice, Bobonong HBC Association and Kopong HBC, using a qualitative research method. It was established that all three organisations experience financial problems. Browning further attests that CHBC in Botswana is funded by NGOs and CBO with little assistance from the government. Guyer (2008:3), in the Huairou Commission of Japan, indicates that financial aspects of HBC are significantly overlooked. If the government overlooks the financial aspects of HBC organisations, sustainability of such organisations will be hampered, for volunteers will not receive remuneration and will thus leave HBC for other remunerated jobs.

HBC organisations in Limpopo receive very limited support from the government: there is little support towards HBC-givers' salaries, which make it difficult for HBCs to carry out their daily responsibilities (Mieh *et al*, [Sa]:198). Hlophe (2006:1990), in a study conducted in the Free State, indicates that the South African DoH has a policy that stipulates conditions for payment of a stipend to volunteer HBC-givers which, according to the findings, does not take place. HBC organisations' services may not improve since they rely only on volunteers due to the issue of stipends, but people need salaries to sustain their families.

According to Jackson (2007:78) caregivers experience financial problems in implementing HCBC. HBC-givers often leave care-giving even after they received training for they expect to receive stipends. Jackson (2007) is supported by Friedman *et al* (2010:74) who noticed a gap in the provisioning of funds for HCBC organisations, for approximately 23% of audited organisations do not receive any funds from either the government or other organisations. Mohammad and Gikonyo (2005:8) confirm that effective CHBC cannot be provided without realistic financial support for transportation, overheads and logistics. CHBC programmes need financial and technical support from the government and NGOs.

- **Transport**

HBC organisations experience transport problems which hamper their caring responsibilities. Caregivers need transport to move around the villages visiting patients. As it was mentioned earlier, most HBC programmes and organisations are based in rural areas which are sparsely populated, patients live far apart and consequently caregivers have to walk for long distances without transport. Lack of

transport for volunteers may impede their ability to deliver adequate services to the patients. Contrary to other researchers' findings, Mabusela (2010:59) revealed that HBC-givers in Mamelodi receive R100-00 per month for transport.

- **Human resources**

Human resources are one of the most important resources in an organisation, for even though all resources can be at hand, no organisation can function without people who can utilise them. However, human resources should be skilled and educated to perform the activities required by an organisation. According to Uys (2003:10) management should ensure that HBC-givers have access to a social worker, a skilled counsellor, a legal assistant and must be able to consult with a trained health care worker on medical issues.

- **Other resources**

The South African DoH (2001:35) lists some basic resources needed in HBC, such as latex gloves, bedpans, catheters, cotton wool, gauze and swabs, bandages and plasters, syringes and needles, disposable towels and nappies, a plastic apron and nutritional meals. Other resources include stationery for administration purposes. HBC-givers must be able to use these resources, which is only possible if they are equipped with the relevant knowledge and skills.

Hlophe (2006:209) found a shortage of resources, especially home-care kits. A lack of resources will have a negative impact on HBC's responsibilities. Without resources like, for example latex gloves, caregivers can be at risk of being infected or pass bacteria to and infecting other patients. According to Mohammad and Gikonyo (2005:10) CHBC programmes are unable to implement and adequately deliver services to their clients due to insufficient resources.

## **2.5 Educational needs assessment**

Nemathaga (2008:141) stresses the importance of continuous education offered to HBC-givers to ensure that knowledge and skills are sustained and to keep up with patients' changing needs and new developments in health issues. The educational needs of HBC-givers should be identified and understood so that they can be

addressed correctly, for if the training needs of trainee HBC-givers are not understood, those needs may be addressed incorrectly (Nduba and Van Acker Hebert, 2005:182) and will not be beneficial to the organisation. Nduba *et al* further indicate that needs assessment can be used to identify relevant problems and to focus on areas of maximum benefit to individual trainees.

Educational needs assessment will create an opportunity for employees to establish what they lack educationally and improve their knowledge, skills and attitudes. The educational needs of HBC-givers should be continuously assessed since the need for new knowledge and information is always present. Nduba and Van Acker Hebert (2005:183) acknowledge that presently there are many developments and constant changes that result in continuous new training needs.

According to Nzimakwe and Xaba (2008:134) needs assessment of caregivers should include their present knowledge and what their expectations are from the training. The training needs of caregivers can be determined by establishing what currently exists and matching it against what should actually be happening now and anticipate future circumstances (Nduba and Van Acker Hebert, 2005:183, 184). Nzimakwe and Xaba (2008:136) state that educational needs should be identified by the HBC-givers and they should be able to explain the gaps in their knowledge. Continuous educational needs assessment will detect what knowledge is lacking regarding caregivers' knowledge and skills, and HBC-givers should in turn become aware of their own educational needs.

Various stages in the needs identification process are outlined by Nduba and Van Acker Hebert (2005:183). Needs must be recognised, communicated and prioritised. Thereafter the organisation should determine how to meet those needs considering the available resources such as finances. Strategies should be implemented to address those needs which should, lastly, be evaluated.

The educational assets of HBC-givers need to be identified to address their needs, which however, might differ according to the type of care they offer. Information on educational needs can be gathered via interviews and discussions where caregivers are able to express their experiences and opinions. Available documents should also be analysed to reveal the educational needs of an organisation.

## 2.6 Educational assets assessment

Assets are the resources, experiences, norms and values, knowledge and skills that HBC-givers can use to enhance their education in as far as health care issues in caring for home-bound, chronic patients is concerned. Green and Haines (2012:9) state that an asset “is a stock that can be built upon or developed, as well as resources that can be shared or transferred across generations.”

The assessment of educational assets can lead to the identification of strengths and resources which can enable the effective operation of an HBC organisation. HBC-givers may not be aware of their educational assets, for some assets may not be fully utilised. Green and Haines (2012:10) highlight that it is authentic to begin with the identification of assets and thereafter assess the needs.

Green and Haines (2012:12) further mention seven forms of assets, namely physical, human, social, financial, environmental, political and cultural assets. HBC organisations and caregivers may possess all these assets, while education and training (human capital) may produce additional benefits for workers (Green and Haines, 2012:12).

According to Green and Haines (2012:117) the asset-based approach builds on the experience and interests of individuals and communities and matches them with the needs and opportunities. The latter may also apply to the HBC-givers where their experience, abilities, capabilities and interests can be matched with their needs. Green and Haines (2012:121) assume that, in human capital theory, people will be willing to invest in education and training necessary to improve their position in the labour market. This can also apply to HBC-givers, for education and training will enable them to be well-informed and thus offer improved quality caring services to home-bound chronic patients.

HBC-givers may possess educational assets that could address their educational needs. These assets might be in the form of public schools, Adult Basic Education (ABET) centres, educational institutions in the health sector, institutions of higher learning, nursing staff, hospitals and clinics, NGOs, religious institutions, CBOs as well as all the available assets in the community.

According to the present researcher, HBC-givers may also possess assets in the form of knowledge and life skills. This knowledge may include:

- Caring for their children
- Caring for themselves when they are ill
- Keeping their houses and family members clean
- Have knowledge of medication for acute conditions, like headache tablets
- Have knowledge on how to take care for their babies and elderly family members
- Know how to cook

HBC-givers are not *tabula rasa*: As adults they are believed to have conceived ideas throughout their lives, which could be beneficial to their caring services.

## **2.7 Definition of key concepts**

### **2.7.1 Home-based care**

Sobuce (2007:3) defines HBC as “an alternative care option for various people including older persons, people with severe functional disabilities, those recovering from illness, terminally ill as well as those living with HIV/AIDS and other debilitating diseases.”

According to Tshabalala (2008:2) HBC is “a service that offers basic support services to sick people who need assistance with the activities of daily living at home.”

For the purpose of this study HBC refers to the caring of home-bound patients by formal and informal caregivers who meet the patients’ clinical, physical, psychological, emotional, spiritual and personal needs.

### **2.7.2 Caregivers**

According to Akintola (2006:239) caregivers “are people who provide care outside the formal healthcare setting and who are not employed or receiving remuneration.”

Van Dyk (2008:406) defines a caregiver as “anyone involved in taking care of the physical, psychological, emotional or spiritual needs of a person infected or affected by HIV/AIDS.”

According to Jooste (2008:33) a caregiver is “anyone who provides care formally or informally.”

For the purpose of this study caregivers are people who volunteer to care for home-bound patients by taking care of their physical, psychological, spiritual and emotional needs.

### **2.7.3 Chronic illness**

Maphula and Mudhovozi (2012:132) define chronic illness as “a disease or other human health condition that is persistent or long lasting in nature.”

The South African Department of Social Development (2010:5) defines chronic as “any condition that lasts for longer than one year and which requires comprehensive and coordinated long term health care.”

For the purpose of this study chronic illness refers to the ill health condition of a person, which is incurable and lasting for as long as the person is still alive. Some chronic patients are home-bound whereas some manage the diseases well and continue with normal life.

### **2.7.4 Educational needs**

Altschuld (2010:4) defines educational needs as “social problems, educational deficits, health care issues, poverty, community relations, drug and substance abuse, violence, and worker motivation.”

According to Opperman and Meyer (2008:35) educational needs are “essential knowledge, skills and attitudes that an individual must possess to perform the work competently, and thereby accomplish the desired results.”

Educational needs as defined by Nduba and Van Acker Hebert (2005:183) is “a discrepancy between an existing set of circumstances and some desired set of circumstances.”

For the purpose of this study needs are aspects that the caregivers lack, and the challenges they experience which hamper the caring of home-bound chronic patients.

### **2.7.5 Educational assets**

Ebersohn and Eloff (2008:27) define educational assets as “skills, talents, gifts, resources, capacities and strength that are shared with individuals, families, schools, institutions, the community and organisations.”

According to Maphutha (2006:16) educational assets refer to “all those valuable resources, skills, strengths and opportunities available.”

For the purpose of this study assets are the resources, skills, abilities, talents, knowledge and capacities that home-based care givers for home-bound chronic patients possess which enable them to provide care effectively.

### **2.7.6 Palliative care**

Palliative care is defined as "the combination of active and compassionate long term therapies and intended to comfort and support individuals and families living with a life threatening illness (WHO, 2002:36).”

Nduba and Van Acker Hebert (2005:166) define palliative care as “the care of people whose disease does not respond to curative treatment.”

For the purpose of this study palliative care is the caring of chronic patients by insuring that they adhere to the treatment of their condition to lessen the pain without curing the condition.



### **2.7.7 Volunteers**

Friedman *et al* (2010:4) define volunteers as “individuals who offer time to perform services for their community without remuneration through a recognised community based organisation.”

For the purpose of this study a volunteer is someone who offers caring services to home-bound chronic patients under an HBC organisation, without remuneration.

### **2.7.8 Community-based care**

According to Ncama (2005:35) Community Based Care is “care that the individual can access nearest to home, which encourages participation by the people, responds to the needs of people, encourages traditional community life and creates responsibility.”

Friedman *et al* (2010:4) define Community Based Care as “the provision of a comprehensive and quality health and social service within the home and community in order to promote, restore, and maintain a person’s maximal level of comfort, social functioning and health.”

For the purpose of this study Community Based Care is the caring of chronic patients, elderly people and physically and mentally challenged people who are home-bound, by HBC-givers, families and the members of the community to assist the patients to manage their condition and ensure that they maintain a healthy life.

### **2.7.9 Home-based care referral system**

Nduba and Van Acker Hebert (2005:36) define the HBC referral system as “an effective and efficient two-way process of linking a client from one caring service to another.”

According to Peu (2008:21) an HBC referral system is “a process whereby clients are referred from one institution to another for continuity of care.”

For the purpose of this study an HBC referral system is a continuous process whereby chronic patients, upon being monitored, are referred to another level which might be

from hospital to community centre, to clinic and to communities (home) or vice versa for continuous assessment and care.

### **2.7.10 Counselling**

Human (2008:86) defines counselling as “a process that enables a person to sort out issues and reach decisions affecting his or her life, or to help a person by creating conditions that will cause the person to understand and/or improve behaviour, character, values or life circumstances.”

Counselling as defined by Nduba and Van Acker Hebert (2005:154) is “a helping relationship between a trained counsellor and a client, in which a trusting relationship and the skills of the counsellor help the clients to understand their problems better and decide how best to solve those problems.”

For the purpose of this study, counselling is a structured conversation between health professionals and HBC-givers, home-bound patients and their families, where the counsellor assists the client to understand and accept the condition that is bothering him/her psychologically and emotionally.

## **2.8 Conclusion**

This chapter highlighted issues in HBC and caregivers, citing literature from other researchers. The South African HBC models were explained and assumptions based on other researchers' findings were discussed. The researcher assumes that HBC-givers lack adequate qualifications, relevant adequate educational training, administration and managerial experience, monitoring and support, as well as funds and resources.

Key concepts had been defined as the following: home-based care, caregivers, chronic illness, educational needs, educational assets, palliative care, volunteers, community based care, home-based care referral system, and counselling. Three definitions were provided for each concept, namely two from different researchers and, for the purpose of this study, the present researcher's own definition. The next chapter will present the research methodology for the study.

## **CHAPTER THREE**

### **RESEARCH METHODOLOGY**

#### **3.1 Introduction**

This chapter highlights the methodology followed in this research project. The aim of this study, objectives, and the research questions to be addressed are already stated in the first chapter, but will be restated in this chapter to guide the research design and methodology employed to explore the educational needs and assets of HBC-givers at Kgotlelelang Basadi HBC Centre. The research employed a qualitative paradigm. The research design includes the population of the study as well as sampling and the sample. Data collection and data analysis strategies employed in this research project will be outlined, and lastly, the ethical considerations that were observed and respected before, during and after the research will be highlighted.

#### **3.2 Aim of the study**

The aim of this study was to explore the educational needs and assets of home-based caregivers for home-bound chronic patients at Kgotlelelang Basadi HBC Centre in order to formulate possible relevant educational programmes.

#### **3.3 Objectives**

- To explore the existing qualifications of home-based caregivers for home-bound chronic patients at Kgotlelelang Basadi HBC Centre.
- To determine the relevancy of the existing educational programmes of home-based caregivers for home-bound chronic patients.
- To contribute towards formulating relevant educational programmes of home-based caregivers for home-bound chronic patients.

### **3.4 Research question**

**What are the educational needs and assets of home-based caregivers for home-bound chronic patients at Kgotlelelang Basadi Home-based Care Centre in the Limpopo Province?**

### **3.5 Design of the study**

This study falls within a qualitative paradigm in the form of a single case study on the educational needs and assets of home-based caregivers for home-bound chronic patients at Kgotlelelang Basadi HBC Centre in the Capricorn District of the Limpopo province.

The qualitative research approach was employed to interview key informants, namely the caregivers, nurses, and home-bound chronic patients at Kgotlelelang Basadi HBC Centre. It was also observed how the carers execute their duties in order to obtain first-hand information. According to McMillan and Schumacher (2010:23) a qualitative research design emphasises that the gathering of data is a naturally occurring phenomenon which also helps in understanding the social phenomenon from the participant's perspective.

Snape and Spencer (2003:3) define qualitative research as "a naturalistic, interpretative approach concerned with understanding the meaning which people attach to phenomena (actions, decisions, beliefs, values and so forth) within their social worlds." In qualitative research the researcher collects data as it occurs naturally. Qualitative research uses multiple methods of data collection to achieve triangulation in order to obtain an in-depth understanding of the phenomenon under study (Bloomberg & Volpe, 2008:72).

Bloomberg and Volpe (2008) are supported by Chilisa and Preece (2005:142) who state that in qualitative research the researcher conduct research on people's experiences in their natural settings, using different data collection techniques such as interviews and observations, and report findings mainly in words rather than statistics. According to Fouché and Schurink (2011:312) research designs in qualitative research

include narrative biography, ethnography, phenomenology, grounded theory and case studies.

For this research, a single case study design was employed, which enabled the researcher to gain an in-depth understanding of the caregivers' educational needs and assets. According to McMillan and Schumacher (2010:344) a case study is a research design in which a single phenomenon is being analysed. "A case study involves an exploration of a bounded system or a single or multiple cases, over a period of time through detailed, in-depth data-collection involving multiple sources of information". McMillan and Schumacher (2010:24) support Creswell (2007) by stating that a case study design examines a case over time in depth, using different available sources of data. Johnson and Christensen (2008:339) affirmed that a case study is an in-depth study of a specific phenomenon, where a substantial amount of data is collected about that case.

The case study allowed the researcher to use different methods and sources to explore the educational needs and assets of HBC-givers.

- **Population**

The Kgotlelelang Basadi HBC Centre serves four rural villages (Makata, Thaba, Ngwanamago and Mmatobole) which are approximately three kilometres from Zoetfontein clinic which serves the centre. Before conducting this study an appointment with the manager of Kgotlelelang Basadi HBC Centre was secured, where the researcher had the opportunity to seek statistical information about carers, patients and nursing staff at the Zoetfontein clinic. The population of this study consists of the caregivers for home-bound chronic patients at Kgotlelelang Basadi HBC Centre. The caregivers are from the four villages served by the centre: Makata = 3, Ngwanamago = 4, Thaba = 5, Mmatobole = 5, with a total number of 17 caregivers. The population also comprises of five professional nurses and three assistant nurses at Zoetfontein clinic. During the course of the study the centre has registered 78 chronic patients from the four villages, of whom 25 were home-bound. The total number of the population is 103.

- **Sample and sampling**

Non-probability purposive sampling was used to ensure that the participants were selected based on their knowledge and experiences in order to acquire valuable information.

“In purposive sampling the researcher selects particular elements from the population that will be representative or informative about the topic of interest” (McMillan & Schumacher, 2010:138). McMillan and Schumacher (2010) are supported by Johnson and Christensen (2008:348), who state that the selection of cases in qualitative research involves purposive sampling where the researcher’s judgement is used to select information-rich participants.

Network or snowball sampling was used since the selected participants, like the professional nurse and the patients, lacked specific information and as such referred the researcher to persons they believed to hold the relevant information. According to Johnson and Christensen (2008:348) in snowball sampling, cases are recommended by individuals who know other individuals likely to yield relevant information-rich data.

In network sampling the researcher selects a few participants who possess information important to the study, and they assist in identifying other persons whom they believe to possess relevant knowledge or information (Chilisa & Preece, 2005:170). The manager of Kgotlelelang Basadi HBC Centre recommended a patient who could be interviewed, but unfortunately this person was uncomfortable to be interviewed, citing that she has only recently come under the care of the Kgotlelelang Basadi HBC-givers. The said patient referred the researcher to her cousin, who has been under care of the centre since 2004.

The sample for the entire population of Kgotlelelang Basadi HBC Centre comprises of the manager, the coordinator, four home-based caregivers, the professional nursing sister in charge at Zoetfontein clinic, and two home-bound chronic patients, totalling nine participants.

### **3.6 Data collection**

The fieldwork stream of data collection was followed, and different methods of data collection were used to gain in-depth understanding of the phenomenon. Documents were analysed, observations were carried out, semi-structured one-to-one interviews were conducted, and a focus group discussion was facilitated.

Before collecting data, the researcher presented Kgotlelelang Basadi HBC Centre with a letter of intent from the Head of the Department of Community and Continuing Education Unit. Together with the study proposal, the letter of intent was handed to the manager and the nursing sister in charge at the Zoetfontein clinic. The purpose of the study, procedures, and significance of the research were explained to them. Ethical considerations, which the researcher planned to observe, were also explained. It was agreed that visits would be arranged by appointment. Permission was granted by the manager and the coordinator for the research to be conducted at Kgotlelelang Basadi HBC Centre. The manager undertook to conduct a meeting with all members of the organisation to inform them about the request, and to identify caregivers who could be interviewed. Permission was also granted for the researcher's assistant to be present during interviews, which would assist in writing responses, taking photographs and tape-recording the interviews.

#### **3.6.1 Phase 1 - Document analysis**

According to Chilisa and Preece (2005:159) documents are used to support evidence from other sources, such as interviews. However Chilisa and Preece (2005:160) also indicate that one of the limitations of documents is being unauthentic.

Written documents which provided insight on the qualifications, job descriptions and operation of the organisation, caregivers' profiles, the constitution and policies were analysed. Other documents which were consulted at Kgotlelelang Basadi HBC were the vision, mission, aims and objectives, patient registers, time register, proposals, donor registers, audited financial statements, minutes for carers and that of the board of directors, asset register, and referral records.

The data obtained from the analysis of these documents could add on to the data provided by the interviews with the respondents and aid in understanding some of the issues from other sources.

### **3.6.2 Phase 2 - Semi-structured one-to-one interviews**

Semi-structured one-to-one interviews were conducted with the coordinator and the manager of the HBC centre, caregivers, home-bound chronic patients, and the professional nurse. Information obtained from these clarified the basis on which caregivers are screened and selected, their existing qualifications, educational needs and assets, and the services offered by home-based caregivers.

The interviews were divided into five separate sessions with each of the participants. Prior to each interview each participant had to sign a letter of consent, indicating their voluntary participation in the study. Permission was obtained from all participants to voice-record their responses together with written notes. Voice-recording would allow for easier analysis at a later stage. All interviewees also granted permission for their photographs to be taken and included in the research report. The research assistant was introduced during each session.

#### **Session 1 - The manager**

Before the interview, and for recording purposes, the researcher re-introduced herself formally and explained the purpose, significance and research ethics of the study. Each participant was assured of confidentiality, and that she could deliberate freely and voluntarily. She was assured that the information would not be used to harm anybody. The assistant was introduced and her role as recorder explained. The manager approved and signed the consent letter. Responses were allowed in both English and Sepedi to create a relaxed atmosphere.

The open ended questions from the interview guide allowed the manager to provide factual information and her opinion on the needed data (*See Appendix 4*). Although she had occupied this position for only a year, most of the questions could be answered satisfactorily. An advantage was that she is one of the founders of the organisation and that she served as finance officer since its inception in 2002.



Since she was unable to respond to some of the questions, especially those concerned with monitoring and support of the organisation, the researcher was referred to the nursing sister in charge of the Zoetfontein clinic. Upon completion of the interview, all responses were verified with the interviewee to avoid misinterpretation. The manager was thanked for her participation at the end of the interview.

## **Session 2 - The coordinator**

The interview with the coordinator took place at the centre in Ngwanamago village. The same introductory process was followed as before. The coordinator was advised to respond in either Sepedi or English, and the consent form was signed. The interview guide used for the manager (*Appendix 4*) was also used for this interview for correlation purposes. The coordinator answered all the questions. The same routine was followed as with the manager when the interviewee's responses were verified, and some facts, which the researcher was uncertain about, were cleared.

## **Session 3 - Professional nurse**

The same introductory procedure was followed as with the previous interviews in which everything was clearly explained, and the consent form was signed.

The interview guide, developed for this particular interview, is attached as *Appendix 10*. The nurse responded to all the questions without difficulty, for she had been in charge of the clinic during the inception of Kgotlelelang Basadi HBC Centre, and *ex-officio* in the interim committee during the initial negotiations of the establishment of the organisation. Having covered all the questions and verified the responses, she was thanked for her time.

## **Session 4 - Caregivers**

One-on-one interviews were held on separate days with the four caregivers at the Kgotlelelang Basadi HBC Centre. After introduction, the caregivers were provided with the details of the study, such as the purpose and significance. The procedure was explained and the confidentiality of the interviews was stressed. Permission was granted for the voice-recording and photographs, and the consent forms were signed.

An interview guide, specially developed for the caregivers, was used (See *Appendix 6*). After each interview the responses of the respondents were verified, and they were thanked for their time and participation at the completion of the interview.

### **Session 5 - Home-bound chronic patients**

The manager of Kgotlelelang Basadi HBC Centre was instrumental in arranging interviews with two chronic patients, each who had been home-bound for a long period. Both agreed to the interview, which was naturally arranged to be conducted at their homes. They live in different villages, namely Ngwanamago and Makata.

Upon arrival at each home, the same introductory procedure and explanations was followed as before, and the consent forms were signed. But, respecting the patients' privacy, the assistant did not accompany the researcher and no photographs were taken. Both patients were comfortable to be interviewed with their family members present, for they are, after all, their primary caregivers.

An interview guide specifically developed for the home-bound patients was used (See *Appendix 5*). They were able to respond to all questions. As before, they were thanked for their participation after their responses were verified.

### **3.6.3 Phase 3 - Focus group discussion**

A focus group interview allows the researcher to understand, determine the range of responses and gain insight into how people perceive a situation (Chilisa & Preece, 2005:151). According to McMillan and Schumacher (2010:363) focus group discussions can aid in obtaining a better understanding of a problem. Johnson and Christensen (2008:349) state that when respondents talk to and hear each other, they are likely to express their feelings and opinions that might not emerge when interviewed individually.

A focus group discussion was facilitated in order to obtain different opinions from the caregivers. Four HBC-givers were sampled from Kgotlelelang Basadi HBC Centre, which included the coordinator, who is also a caregiver. The interview was held at the Kgotlelelang Basadi HBC Centre.

The usual introduction and statement of purpose, significance, etc followed, and the assistant was introduced. The group was ensured that information is confidential and that responses could be given in the language of their choice. All signed the consent forms.

The researcher facilitated the discussion, took notes and simultaneously studied the body language of the respondents. The voice-recorder was operated by the assistant who also took photographs. An interview guide was used (*See Appendix 9*); and their responses were verified. At the close of the interview, they were thanked for their cooperation.

#### **3.6.4 Phase 4 - Observations**

According to McMillan and Schumacher (2010:350) observation is a way for the researcher to see and hear what is occurring naturally in the research location.

The observation phase was divided into two sessions to support the data collected from document analysis and during interviews. Before these sessions took place, the researcher introduced herself and her assistant, followed by protocol. The manager informed the caregivers that they would be monitored while performing their duties. Since none had any objections, the researcher could select the caregivers whom she wanted to observe.

The first session was dedicated to examining the facilities, structure, equipment, and infrastructure at Kgotlelelang Basadi HBC Centre. The second session was spent in observing the caregivers while performing their duties, with the specific intention to see the circumstances under which caring activities takes place and the manner in which it is performed. This would enable the researcher to observe the abilities, knowledge, skills and processes, as well as educational needs of the caregivers.

During the usual introduction – including statement of purpose, the assurance of confidentiality, and so forth – the patients were assured that no photos would be taken. The observation process was explained to both the caregivers and patients, who signed the consent forms.

It was made clear in the explanation that the researcher was going to observe behaviour in order to assess the educational needs and assets of the caregivers. The researcher would be a non-participant observer, who would merely listen and watch to draw conclusions. All caregivers, patients and their families were thanked afterwards.

Three HBC-givers of Kgotlelelang Basadi HBC Centre were observed on separate days. Each observation started at a patient’s home, for which an appointment was secured through the manager.

### 3.7 Data analysis

Qualitative data analysis is primarily an inductive process of organising data into categories and identifying patterns and relationships among the categories (McMillan & Schumacher, 2010:367). These authors (2010:369) further state that organising data separates it into a few workable units.

The wealth of written and transcribed data had to be reviewed, condensed and categorised and coded according to the participants’ responses. For this purpose a data matrix was used. A data analysis grid is a useful way of organising qualitative data in order to facilitate report writing (Chilisa & Preece, 2005:172). The data matrix is based on each of the participant’s responses.

**Table 1. An example of the data matrix used in the study**

VARIABLES	RESEARCH PARTICIPANTS				
	Project manager	Coordinator	Caregivers	Nurses	Patients
Training received	<i>Response</i>	<i>Response</i>	<i>Response</i>	-*	-*
Monitoring and support	<i>Response</i>	<i>Response</i>	<i>Response</i>	<i>Response</i>	-*
Administration and managerial experience	<i>Response</i>	<i>Response</i>	<i>Response</i>	<i>Response</i>	<i>Response</i>
Funds and resources	<i>Response</i>	<i>Response</i>	<i>Response</i>	-*	<i>Response</i>
Adequate qualifications	<i>Response</i>	<i>Response</i>	<i>Response</i>	<i>Response</i>	<i>Response</i>

*\*Blank spaces indicate that a response was not expected from participants since the particular variable is not of relevance to them.*

### **3.8 Ethical considerations**

Punch (2009:102) states that research ethics are a set of guiding principles to assist researchers in conducting ethical studies. According to Strydom (2011:117), when subjects are involved without their consent, their right to termination is impaired. Strydom (2011:118) further maintains that informed consent ensures the full knowledge and cooperation of subjects, while also resolving, or at least relieving, any possible tension, aggression, resistance or insecurity in the subjects.

Before embarking on the research a letter of consent was obtained from the head of the Community and Continuing Education Unit at the University of Limpopo which was handed to the manager of the Kgotlelelang Basadi HBC Centre. The purpose and significance of the study was explained to the participants before obtaining written consent from each of them. Participants were briefed on their role, and they agreed to be recorded and to be photographed.

Punch (2009:119) states that assuring anonymity means not revealing the participants' identity. The participants' privacy is protected by ensuring that anonymity, confidentiality and appropriate data storage was and will be maintained before, during and after the research process. Participants' names are only known to the researcher. A relationship of trust and respect with the participants was maintained and personal biases were set aside throughout the investigation. Participants were also informed that participation is voluntary and that they are free to withdraw from the study at any time. The participants' responses were verified with them after each interview.

### **3.9 Conclusion**

In this chapter the aim of study, research question, sub-questions and objectives were stated. The research methodology was explained. The research design, which comprises the population from which the sample was obtained, the sampling method and the sample were described. Data collection and data analysis methods and strategies were highlighted. An example of a data matrix that was used to categorise and organise data was presented. Ethical considerations observed before, during and after the research was outlined.

## **CHAPTER FOUR PRESENTATION AND ANALYSIS OF FINDINGS**

### **4.1 INTRODUCTION**

This chapter presents the findings of the data collected at the Kgotlelelang Basadi HBC Centre. Findings were obtained via interviews, document analysis and observation of caregivers performing their duties. The Kgotlelelang Basadi HBC Centre manager, coordinator, HBC-givers, professional nurses and home-bound chronic patients were interviewed. A data matrix was used to analyse the findings (*See Appendix 11*) which are based on the aim and objectives as well as the questions which stemmed from the study.

- **Aim of the study**

The aim of this study is to explore the educational needs and assets of home-based caregivers for home-bound chronic patients at the Kgotlelelang Basadi HBC Centre in order to formulate possible relevant educational programmes.

- **Research question**

What are the educational needs and assets of home-based caregivers for home-bound chronic patients at Kgotlelelang Basadi Home-based Care Centre in the Limpopo Province?

- **Sub-questions**

- What are the existing qualifications of home-based caregivers for home-bound chronic patients at Kgotlelelang Basadi HBC Centre?
- How relevant are the existing educational programmes of home-based caregivers for home-bound chronic patients?
- Which aspects can be considered towards formulating relevant educational programmes of home-based caregivers for home-bound chronic patients?

## **4.2 General background - Kgotlelelang Basadi Home-based Care Centre**

The Kgotlelelang Basadi HBC Centre is registered as a Non-Profit Organisation (NPO) under the Department of Social Development. The organisation was initiated in 2002 by the nursing sisters at Zoetfontein clinic in an attempt to reduce the defaulting rate of tuberculosis and HIV/AIDS and other chronic patients. They had contacted the traditional leaders of Ngwanamago, Thaba, Matobole and Makata villages to recruit community members who would be interested in volunteering to care for the ailing people of the four villages. According to the sister in charge of the clinic, only four people volunteered.

The organisation started under a tree inside the clinic yard, for no vacant rooms were available to accommodate them.

- **Kgotlelelang Basadi logo and mission**

The logo of Kgotlelelang Basadi HBC Centre is “Care of Life and Environment.” The organisation has a clear mission and vision, which unfortunately is not displayed where everybody who enters the centre, can read it.

The mission of Kgotlelelang Basadi HBC Centre is stated as follows:

- “To mobilise community members to determine health needs and take responsibility to access health care and health resources”.
- “To be a representative and to coordinate the needs of people through advocacy, information and referral”.

The policy of Kgotlelelang Basadi HBC Centre clearly states the different roles of the manager, coordinator, the finance officer, driver, caregivers and board members. However, it was evident that board members were uncertain about their responsibilities. A number of successive meetings were held with the DoH Capricorn District at the centre. The manager was asked to meet with the chairperson of the board, since he interferes in the manager and finance officer’s duties. It became evident, from the documents studied, that board members are not familiar with their functions and responsibilities.

The policy states that the organisation is guided by the following values:

- Honesty
- Integrity
- Confidentiality
- Professionalism
- Efficiency
- Accountability
- Transparency and
- Participation

### **4.3 Findings from documents**

#### **4.3.1 The role of Kgotlelelang Basadi HBC-givers**

The role of caregivers is stated as follows:

- To promote and maintain the health of a patient
- To promote and maintain the patient's hygiene
- Monitor the patient with regard to treatment
- Assist in household chores if the patient does not have anyone to help
- To care for the dying patient
- Offer health education to the community
- Keep records of what the caregiver's duties are each day
- File and submit reports to the coordinator every Friday
- Attend meetings with management and clinic staff
- Works from Monday to Friday, 08h00-16h00, except in exceptional cases.

#### **4.3.2 Caregivers' age and gender**

The caregivers' ages range between 34 and 64 years, including the manager, coordinator and finance officer. These ages show that a high number of caregivers are between 40 and 64 years, which prove that young people are not interested in joining the organisation.

According to the manager, one caregiver, aged 64, do not have patients allocated to her for she errs when caring for patients. It is the opinion of the manager that it is due



to her age, and that she does not understand modern approaches to caring. Although she is responsible for cleaning the premises, the researcher was witness to the dirty and unhygienic situation. Apparently the caregiver does not turn up at work regularly, but earns the same monthly stipend as the other caregivers. The manager, however, indicated that she will not be discharged as long as she wants to work, for she was the first person to volunteer her care giving services without any stipend.

Kgotlelelang Basadi HBC Centre has 17 caregivers: one male and 16 female. The management consists of a finance officer (male) and the manager and coordinator (both female).

The coordinator reasons that the small representation of men in the organisation is due to the lack of a fixed salary, for men are usually responsible for the upkeep of their families and therefore need a dependable income. Akintola (2006:242) states that many male caregivers do not stay as long as female caregivers, for they are usually unable to cope with the ailing patients. Apparently men seem to view HBC as something to be practiced by unemployed women. Furthermore, traditional culture excludes men from doing household-chores, an aspect which prevents them from volunteering HBC. Added to this is the fact that traditionally women are responsible for the care of ailing people; men often are absent from home due to job demands.

It is apparent that the main reason for caregivers volunteering their services is to receive remuneration for their service. Patient care is only of secondary importance to them. Nevertheless, more than 50% of the caregivers qualified to study further on health issues.

The following table shows the range of HBC-givers' ages.

**Table 2. Ages of caregivers**

<b>AGE</b>	<b>NUMBER</b>
34-39	5
40-49	8
52-56	3
64	1



*Figure 1. Six of the Kgotlelelang Basadi Home-based caregivers.*

#### **4.3.3 Educational level of home-based caregivers at the Kgotlelelang Basadi HBC Centre**

Only five caregivers out of 20, including the manager, finance officer and coordinator had passed Grade 12. The lowest grade passed by the remaining 15 participants is Grade 8 (previously Standard 6). The fact that all caregivers are literate is an asset; for this allows them to study further or even register with ABET centres to improve their educational level. Only the manager and finance officer have tertiary qualifications. However, analysis has shown that the majority of caregivers are literate and are thus able to read and understand medication instructions, up to a certain level. The following table shows the educational levels of the caregivers including the manager, finance officer and coordinator.

**Table 3. Educational level of caregivers**

<b>Educational level</b>	<b>Number of caregivers</b>
Tertiary level	2 (manager & finance officer)
Grade 12	3
Grade 11	4
Grade 10	4
Grade 9	5
Grade 8	2
<b>Total</b>	<b>20</b>

#### **4.3.4 Adequate qualifications**

The caregivers' profiles show that none of them have any relevant qualifications, except for certificates issued after attending short training courses (e.g two weeks) and workshops.

It is evident that HBC-givers do not have any professional knowledge concerning health issues when they start working, except for basic knowledge that they acquired through life experiences. This raises serious questions in terms of the quality of services offered to patients. The assumption is that a lack of relevant qualifications will compromise the caring service.

#### **4.3.5 Other documents**

The constitution of the organisation includes meeting issues, working hours, roles of all stakeholders and policies. Other available documents include the time register, financial reports, monthly patients' reports, assets register, patients' records, vehicle log book, and copies of funding proposals. Except for the time register and vehicle log book which were not up to date, some of the patients' reports from the previous month were also not available.

## **4.4 Findings from observation**

### **4.4.1 Infrastructure**

The Kgotlelelang Basadi HBC Centre does not own any buildings. It operates from a dilapidated building which was once used as a bakery. All activities, except for administration (filing, report and proposal writing) is done at the clinic, for the centre has no electricity or security. Apparently the electrical cables were stolen before the HBC centre occupied the building. The clinic accommodates the organisation in a small room furnished with computers, two cabinets, a table and three chairs for administration purposes. All other activities such as planning, submission of patients' reports by caregivers, meetings and distribution of food parcels to orphans and patients take place at the centre itself, where there is sufficient furniture. These two premises are at least two kilometres from each other.

Operating from two different venues may hamper the smooth running of other activities. For example, if documents need to be printed during a meeting (at the centre), the responsible person has to go to the clinic, two kilometres from the centre; caregivers report at the centre and then have to collect their caring equipment from the clinic. That is inconvenient, for the caregivers usually travel on foot, for they cannot afford transport. The centre also lacks toilets and water. During special events they have to organise water and hire mobile toilets. The building is totally unsuitable for such an organisation.

### **4.4.2 Equipment and facilities**

The DoH supplied the organisation with a computer, printer, and two laptops, which cannot be used at the centre, due to the building's lack of electricity. The organisation owns eight office chairs, a computer stand, two desks, 20 plastic chairs and three filing cabinets.

A vehicle, a light delivery van ("bakkie") was donated by the National Lottery. However, the log book is irregularly completed. The coordinator indicated that the driver often forgets to complete the information and signs it before a trip is made. This indicates unauthorised trips and poor management despite a clearly stated car policy.

#### 4.4.3 Observation at patients' homes

Two of the caregivers showed empathy and compassion as they greeted their respective patients and enquired whether they had slept well during the previous night and whether they took their evening medication. They enquired on whether they ate supper and breakfast, washed themselves, brushed their teeth, and checked whether the houses, clothes and bedding was clean. The patients and their primary carers were also asked whether the patient has shown any reaction to the medication, the tablets were counted (to ensure that there was no slip-up), all the while observing their patients. These caregivers respectively spent between 30 and 45 minutes at the patients' homes.

The other caregiver did not show respect or compassion and did not even enquire about the patient's night; she only instructed the patient to take the medication and thereafter completed the patient's record form and left. She is either inexperienced, not well trained or neglecting her duties. The patient is an elderly man living with his grand children aged 7 and 17 (their parents are employed in Gauteng). He indicated that the caregiver does not visit him regularly.

*"Don't see if she came today with you. She does not visit me regularly. My grand children do not give me my medication on the required time. They leave me without porridge."*

This gave me an impression that some caregivers neglect their duties. From these observations it is clear that some caregivers are not trained or are inadequately trained, or don't really have compassion for their patients, for they do not even touch their patients. However, the coordinator pointed out the fact that, during workshops conducted by the DoH, caregivers are told to avoid touching their patients or to clean their rooms. Except for the patients' records, they had no equipment (e.g latex gloves, thermometers, bandages or scissors) which are distinctive of health workers.

## **4.5 Findings from interviews**

### **4.5.1 Adequate qualifications**

According to the manager and coordinator no specific qualifications are required to become a caregiver; anyone can become a caregiver as long as the person is literate, don't divulge secrets and is willing to do this on a voluntary basis.

One of the roles of HBC-givers is to educate the community on health issues, including facts on different diseases and hygiene. This means that they need to be knowledgeable, well-informed and conversant in patient care, treatment, and related matters in caretaking. This kind of training can be mastered by a person who passed Grade 12. It is self-evident that caregivers will not be able to perform health care services effectively if they do not possess any relevant qualifications.

The manager, finance officer, and the coordinator also do not have relevant managerial qualifications. Both the manager and finance officer were caregivers appointed in these positions. Both had passed Grade 12 and respectively possess a certificate and diploma in computer studies. Both these managerial positions need relevant qualifications. The coordinator passed Grade 10.

- **The manager**

The manager highlighted that it is stipulated that a portion of the money received from the National Lottery should be allocated for the development of caregivers: each of them receives R3000 annually to study and develop skills, depending on the availability of the allocated money that the organisation has applied for from the National Lottery. However, they are reluctant to continue with their studies despite efforts by the manager to motivate them. They demand the money allocated to them for their personal use. Only the manager had used the money during the previous year to enrol for an advanced certificate course in computer studies.

The manager is of the opinion that the caregivers do not understand procedures and issues due to insufficient education. An example she mentioned is that, even though the budget and financial statements are reported to them, they still insist that she deviate from the budget and the directives of the funders. She also mentioned some caregivers are even unable to complete their contract details on forms, such as those

provided by the Extended Public Works Programme (EPWP)<sup>1</sup> which needs to be completed quarterly. The caregivers ask the manager to complete it for them.

It is the opinion of the researcher that HBC-givers should at least have passed Grade 12; this would qualify them to be trained for higher level certificates and diplomas in health studies at recognised institutions of learning, or it might be an opportunity to enrol as assistant nurses.

The manager alluded that sometimes, when she provides feedback from workshops, the caregivers query her. Some of them complain that they don't receive their stipends from the DoH, accusing her and the coordinator of misappropriating it. She always explains to them that those caregivers, who didn't receive stipends, were not part of the organisation at the time she completed and submitted the proposal to the DoH, i.e the funds allocated to the organisation for a three-year period does not include those particular caregivers. The fact that they insist on being paid could be due to their insufficient education. Apparently the unpaid caregivers were not properly informed that they were not included in the approved proposal, for they joined the organisation only after the proposal was approved. They also revealed that they don't have any home-based care qualifications; they were never asked whether they have any qualifications when they volunteered.

- **The coordinator**

The coordinator, even though she only meets the criteria for Grade 10, supports the manager on the issue of caregivers doubting management's feedback from workshops and meetings. She thinks it would be a good idea to invite the caregivers to attend all management meetings and workshops in order for them to report to their colleagues.

- **The caregivers**

The caregivers seem to be satisfied with their education level for they do not bother to register at ABET centres. Some indicated that they are too old to study whereas others

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<sup>1</sup> The stipends of the HBC-givers are funded by the EPWP, for they are part of the South African government's EPWP which, according to DSD (2012:27), is a national programme that covers all spheres of government programmes where HCBC is one of the leading pilot programmes for the social sector. The EPWP transfer stipend funds to the DoH and the Department of Health administer these funds.

said that they do not have time. They indicated that they cannot afford to work, take care of their families and study at the same time.

#### **4.5.2 Training programmes**

Data from interviews with the management, which include the manager, coordinator and finance officer, testify that none of them received adequate training. Both the manager and coordinator received two days' training in compiling reports and managing funds, which is definitely insufficient.

- **The manager**

The manager further mentioned that they often attend day long workshops, which is seen as too short for all the content to be mastered being compressed into a few hours. It was mentioned that the finance officer has only been appointed since October 2013, which explains why she has not yet received any training. The caregivers are also not well trained, receiving training only for a few weeks, often only one or two days. The only yearlong training caregivers receive is that offered by Ancillary Health Care, which is presented in block sessions. However, the caregivers who completed the training did not receive certificates.

The following table shows the different types of training received by caregivers, including the manager and coordinator. The training seems to be insufficient, for caregivers do not take care of patients as a group, but as individuals. They don't have the same training programmes or are equally well-trained, for each caregiver undergoes different training. This raises questions about the quality of care they provide to patients with different chronic conditions considering the fact that each caregiver is allocated patients and has to offer the services unaided, since the other caregivers are occupied with their own allocated patients.



**Table 4. Type and duration of training received by caregivers**

Type of training	Duration	No. Trained
Ancillary Health Care	1 year	10
HIV/AIDS	1 week	2
TB	1 week	4
Counselling	1 day	1
Breast feeding	1 day	10
Home-based care	2 weeks	1

For example, the table above indicates that only two caregivers completed a one-week training course on HIV/AIDS. Interestingly, the DoH was prompted to develop and implement HBC specifically to heed diseases such as HIV/AIDS and other communicable diseases, like tuberculosis, which leads to the overcrowding of health institutions. The DoH (2001:2) indicates that South Africa lacks sufficient health care resources, while the AIDS epidemic further impacts negatively on these inadequate resources.

- **The caregivers**

The majority of HBC-givers indicated that they have patients on Anti-Retroviral Treatment (ART), yet they were not trained or are inadequately trained to care for HIV/AIDS patients. The DoH (2003:59) emphasises the provision of comprehensive care and treatment for people living with HIV/AIDS in South Africa. Van Graan *et al* (2009:312) also recommend that caregivers' training should be a continuous and sustainable process. The Kgotlelelang Basadi HBC-givers do not receive continuous training. It is evident from the interviewee responses and document analysis that the HBC-givers of the Kgotlelelang Basadi centre do not receive adequate training on different diseases and HBC as a whole and that the quality of care provided by untrained caregivers is compromised.

In the researcher's opinion, all caregivers should be trained comprehensively on HIV/AIDS to enable them to offer quality care and educate the community on prevention and care.

Van Graan *et al* (2009:312) state that community-based caregivers who complete any training or course should be awarded certificates to enhance their motivation. HBC-

givers can use the certificates received during training to find other jobs or to further their studies.

Ten caregivers attended an ancillary health care course in 2009, but stated that up to 2014 no certificates were issued as proof of completion of the course. The following are some comments on the issue:

*“Since we have been trained in Ancillary Health Care, we did not receive certificates as evidence that we were trained. We need to produce certificates when we look for other jobs.”*

The fact that caregivers are not awarded certificates confirms that the DoH does not take caregivers seriously or value their services. Certificates might boost caregivers' self esteem for it will be proof that they are qualified for their jobs.

In the researcher's view, the DoH, as the body who offers the training, does not conduct a needs assessment regarding the courses/workshops/programmes to be offered or how to conduct such training. Furthermore, the caregivers' level of education and comprehension is not considered when planning such training programmes, because a person with little education is not able to grasp essential information in limited time. This often leads to abandonment of the course after only one day's attendance

According to Hlophe (2008:209) HBC-givers lack training and sufficient skills to provide effective home care and support, despite the fact that they deliver an important, sensitive, and hazardous service.

The researcher is of the opinion that caregivers should receive proper training, covering both chronic and acute conditions, which will enable them to care properly for any patient. Lack of knowledge and skills may put both patients and caregivers at risk of being infected by different chronic and communicable diseases. During the focus group and one-to-one interviews, the caregivers indicated that they are concerned about their inadequate knowledge concerning different diseases and as such are not confident when offering their services. In addition, some community members humiliate them by saying that they are uneducated because they did not go to nursing college.

Caregivers pointed out that, due to lack of training, they are unable to perform some of the duties - as stipulated by the policy - such as offering community education and caring for dying patients. Furthermore, they also don't receive training on the administration of medication, or how it should be taken. Both the manager and nurse agree that caregivers should know the medication prescribed for different diseases by name as well as its side effects. However, the caregivers indicated that they are unfamiliar with some of the medication, for patients usually receive it in their absence. Often, they see the medication only upon requesting to see it.

The Kgotlelelang Basadi HBC-givers rely mostly on the information they share amongst themselves and the little bit that they receive from the clinic. It is evident that the training programmes are relevant but inadequate, not equipping caregivers with sufficient knowledge and skills.

Another issue that emerged during data collection is that Phelophepha, a Healthcare Train Project which was established in 1994 by Transnet, was looking for caregivers aged between 18 to 35 years, to be trained in a programme entitled "Prevention of HIV from Mother to Child". Only two caregivers from Kgotlelelang Basadi qualified, for the rest are older than 35 years

Quality training will provide confidence to HBC-givers when caring for patients. Sobuce (2007:51) indicates that trained volunteers have a sense of belonging and status, and also feel valuable to the organisation. After attending a course, caregivers should provide feedback to other caregivers and also organise community training.

#### **4.5.3 Administration and managerial experience**

Kgotlelelang Basadi HBC Centre has a board of directors and a manager responsible for coordinating the organisation's activities. Records of meetings, caregivers' profiles and patient records are well kept. The manager is responsible for the administration of the funds and assists in drafting the budget.

- **The manager**

However, the manager indicated that the caregivers do not execute their duties according to policy and are uncooperative: some do not visit their patients regularly,

they sometimes do not attend meetings or honour events and campaigns, such as the HIV/AIDS awareness campaign, organised by the organisation. Some caregivers do not adhere to an eight hour workday as stipulated by the policy. Often they do not visit their patients but complete the patient's monitoring form, sign it and even forge the patient's or family members' signatures. The caregiver's records would show that all patients had been visited, while some patients' relatives would complain that they are not regularly visited. Often a patient's relatives collect their medication from the clinic whereas it is the responsibility of the caregivers to do that.

The manager also said that board members interfere with her work and argue over the organisation's funds. They expect to be remunerated each month, which is against DoH and DOS policy. Furthermore, she revealed that board members believe that she misappropriates the organisation's funds, which explain why they don't get their share, even though they are presented with the funders' instructions. Consequently they do not want to authorise cheques, even when motivated by the manager. Furthermore, the board signs the cheques for the caregivers' stipends and management's salaries, which they sometimes sign a week after it was due.

This attitude hampers the smooth running of the organisation. Additionally, National Lottery funding stipulated the allocation of funds with time-limits to be kept. For example, a percentage of the funding should be allocated to food parcels for the patients, which should be utilised within a specific period (subdivided into months and quarters of the year).

The board members also interfere in the organisation of events and campaigns, especially when food parcels are distributed to patients and orphans, which they want to claim for themselves. The caregivers also demand food parcels, citing reasons that they receive only modest stipends.

According to the manager, the board members also manipulate the caregivers to oppose her: they declared her unqualified for the position; they even once promised some caregivers the managerial position when she stood to be fired by the board. It is apparent that the board members' influence on the caregivers resulted in them defying the manager and not performing their duties as prescribed by the DoH. Board members accuse her of not heeding them for they want her to agree with them in

everything they say, whereas her views and ideas are dismissed even though she is supported by the policies. It is difficult to manage the caregivers for some of them are not cooperative:

*“Some caregivers undermine my authority. They do not adhere to working hours. Even when they submit reports on Fridays they come very late, and there is nothing I can do as they even say some nasty things about me and swear at me”.*

The following is an example of the uncooperativeness of board members as expressed by one of the caregivers. The manager also shared the same sentiments on the situation.

*“Sometimes we don’t get paid in time as the chairperson does not want to sign the cheques. We have to plead with him before he can sign. They say they want to be paid for being board members, which is against the policy of the Department of Social Development. They hold meetings only when there is something that they think is not properly done.” They do not support us. Their meetings do not have an agenda, and can sometimes take four to five hours as there is no order.”*

- **The caregivers**

All disputes such as lack of cooperation and team work hamper the progress of the organisation. The manager would like to see the organisation expanding, which would include several projects. However, at the time of the research being conducted, the only existing project was that of care giving.

Nevertheless, the manager pointed out that they intend to embark on a greenery project. The National Lottery also instructed them to use R60 000 to purchase sewing machines and employ a fashion designer who could teach some residents, the caregivers excluded, to sew and sell their products to sustain the project. The progress of the project is, however, hampered by the insistence of some caregivers to be included in it and taught to sew, for they believe that the National Lottery funded the organisation because of them. But according to the National Lottery instructions, caregivers are already members of the organisation and are thus excluded from the sewing group. New members should be recruited for the sewing project, which is aimed at empowering and alleviating poverty and unemployment in the community.

The organisation does not regularly organise awareness campaigns on health issues, an undertaking which should be facilitated by management. It was further established that neither the manager nor the coordinator are conscientious about their timely arrival at work, for often during research, the researcher were told that either was still at home and would be at work at 10h00. It shows that they don't lead by example.

Caregivers in turn complained that the manager and coordinator impose decisions on them without seeking their opinions, views and initiatives. They further stated that management does not want caregivers to convene meetings with board members even though they have grievances. However, according to the manager, board members are not allowed to convene meetings with caregivers, who can only convene meetings with management.

It is evident that neither the board members nor caregivers are cooperative. The manager even attributes her miscarriage to the stressful situation created by the board members and caregivers.

From the collected information it is clear that the manager and board members lack managerial skills. She is unable to stabilise the situation, which would be possible if all stakeholders in the affairs of the organisation could become involved, thereby ensuring transparency; internal workshops for all involved in the organisation would clarify the policies and procedures to be followed.

In the researcher's view, the manager lacks conflict management skills. Additionally, the manager's lack of relevant qualifications together with the fact that she once was an HBC giver – which is not a profession but a voluntary act – may be the reason for board members and caregivers not respecting and cooperating with her.

It is clear that neither the caregivers nor board members are conversant with their particular roles and responsibilities, such as caring for patients, completing patients' progress forms, when and how to convene meetings, supervising the activities of the organisation and taking informed decisions, fundraising and developing the organisation. The manager, caregivers and board members all lack administration managerial experience and are therefore unable to sustain professional and sound relationships in the organisation.

#### 4.5.4 Monitoring and support

Although the main purpose of the DoH Capricorn District is to monitor administration and finances, the organisation is also monitored and supported by them. Monthly reports, compiled by the manager and coordinator, are submitted to the DoH with the intention that the caregivers receive their stipends as incentives.

DoH officials evaluate and monitor the organisation twice yearly. Nevertheless, they don't monitor the caregivers' services, since they rely on the written reports without verifying what is happening at the patients' homes. Caregivers mentioned that they never meet with the DoH; the DoH also does not arrange workshops or training sessions in support of the services provided by the organisation.

From the above statement it is clear that the caregivers' services lack monitoring on behalf of the DoH.

Research revealed that caregivers do not visit patients regularly but complete the patient's monitoring form and even sign on behalf of them as evidence of the visit. This was confirmed by one of the interviewed patients who indicated that his caregiver can even skip a week without visiting him, and on her return will only enquire whether he had been taking his medication regularly.

The clinic also does not do much to monitor the services of HBC caregivers. According to the professional nurse, the clinic allocates patients to the caregivers and thereafter only relies on their written reports. However, sometimes they neglect their work and patients default on their medication and develop complications. The manager said:

*"The nurses do not workshop us. They only give the caregivers instructions on how the specific patients should take their medication. The main thing that the clinic does is to allocate patients to caregivers, and sometimes the nurses conduct door-to-door visits with caregivers to look for patients who do not want to be diagnosed."*

Caregivers mentioned that they do not receive referral letters from the clinic stating all the details of patients. Apparently the nurses only provide them with an address and name of a patient. Sometimes they discover new patients when moving about the villages, which are then taken to the clinic for diagnosis and put on treatment. The new patient is then added to the HBC list and, without any documentation, has to be cared

for. However, the manager indicated that the National Lottery, one of their funders, advised them to submit referral letters from the clinic to patients who received food parcels. Unfortunately, no referrals could be found.

It is apparent that the clinic is not much involved in HBC matters. The nurses allocate new patients to the caregivers but do not monitor patient care. This is deduced from the fact that the nurses indicate that many patients fail to use their medication according to prescription, for caregivers do not visit their patients regularly. The relationship between the clinic and the organisation is not stable, for the two organisations operate parallel to each other: no meetings are convened to discuss patients' progress and problems. HBC-givers are exposed to situations like witnessing critically ill or dying patients, which affect them emotionally and psychologically. There is thus a need for proper counselling, but although they have a mentor among them, she does not offer adequate counselling.

No or inadequate monitoring relates to limited support, a fact proven by the inadequate training of caregivers. This creates a feeling of neglect which leads to demotivation.



**Figure 2.** *The focus group interview.*



#### **4.5.5 Finances**

- **The manager**

At the time of this research and according to the manager, Kgotlelelang Basadi HBC Centre had no financial problems. The organisation secured funding from the National Lottery together with directions on the application of the funds. The manager and finance officer drafted a budget which was presented to the board members for approval. The funds were allocated for the salaries of the manager, coordinator, finance officer, the caregivers' and driver's stipends, skills development and education of caregivers, food parcels for patients, school uniform for orphans, stationary, and petrol for transport. The rest went towards the acquisition of a vehicle.

The DoH funds the organisation on a three-year contract basis. Towards the end of this period, a proposal for further funding for the following three years is submitted.

The DoH also funds the salaries of the manager, coordinator and finance officer. The money is deposited into three tranches: the first tranche for six months and the remaining six months divided into two tranches. The caregivers' stipends are funded by the Department of Public Works as part of EPWP while the driver's is funded by the National Lottery. EPWP transfers the funds to the DoH, which then deposits it into the organisation's account in four tranches of three months each. However, the manager and caregivers complained that it takes a while for the departmental money to be processed, which leads to a delay in payment of stipends and salaries. One of the caregivers said:

*"It was difficult before we were funded by the National Lottery because we used to spend many months without salaries. It takes time for the department money to be deposited. Now we are being assisted by the money from the National Lottery whilst we are still waiting for that of the department."*

- **The coordinator**

Contrary to the manager's statement, the coordinator mentioned that the funds they receive are still insufficient to provide in all the necessities and activities of the organisation, especially the stipends. This is supported by the caregivers who indicated that they are dissatisfied with the small stipends: they receive R1300 from the National Lottery and R1400 from the DoH; the total amounting to R2700. They feel

that the money is barely enough, considering the fact that they are at risk of being infected by communicable diseases and work under stressful conditions, for they see patients who die under terrible circumstances. This is confirmed by Akintola (2006:242) who states that the nature of care-giving activities by women put them at risk while caring for PLWHA. The caregivers further stressed the difficult and risky situations they are exposed to, for sometimes male patients insult and threaten to beat them if they do not want to take their medication. One caregiver revealed that a male patient once threatened to rape her if she continued visiting him.

Although the organisation currently doesn't experience financial problems, the foreseeable future might produce some problems, for they do not have any other income generating projects, like in neighbouring HBC centres, where vegetable gardens, sewing and a bakery alleviates the situation. She does not know what will ensue should the National Lottery not fund them again.

#### **4.5.6 Other resources and equipment**

- **The manager**

The caregivers do not have access to all the necessary resources used in caring for patients. They sometimes attend to patients without protective clothing such as latex gloves, masks, and related resources like disinfectants. This hampers their work and put them in danger of becoming infected or infecting other patients. The clinic is responsible for providing resources like latex gloves, bandages, gauze, anti-bacterial solution, cotton wool, and masks. However, the caregivers indicated that sometimes the clinic runs short of supplies for extended periods. Due to poor training some resources, such as catheters and thermometers, cannot be used by the caregivers. This will definitely compromise the quality of HBC services. However, according to the coordinator caregivers are instructed by the DoH not to touch, clean or feed patients, but should only monitor the administration of medication and counsel patients. The lack of the above resources should therefore not hamper their caring activities, although they still need resources such as masks for they spend some time in patients' bedrooms. This is contrary to what the researcher found in the organisation's documents, which stipulates that one of a caregiver's roles is to assist in household chores if the patient does not have anyone to assist or care for a dying patient.

Caregivers collect resources like latex gloves, bandages and disposable nappies from the clinic (if available) and distribute them among the families of patients who need it. However, some patients do not have families who can adequately take care of them - like those who are being cared for by elderly people or children - and as such the caregivers feel they should help such patients. These caregivers need those resources for their protection even though, according to the coordinator, they are not supposed to do anything else but to monitor patients.

During this research it was discovered that Kgotlelelang Basadi do not engage in fundraising to supplement the resources supplied by the DoH and other NGOs (like the National Lottery) to sustain the organisation. The manager's remark that the funds allocated for petrol will soon run out, and that they are uncertain whether the National Lottery will approve their proposal for the next financial cycle, it is evident that they do not have any fundraising skills.

#### **4.6 Conclusion**

An overview of Kgotlelelang Basadi HBC Centre was presented in this chapter, with focus on the presentation and analysis of the study's findings. The findings, obtained via interviews, observations and document analysis, were structured around various themes such as age and gender of caregivers, educational level, training programmes, managerial experience, monitoring and support, finances, and other resources.

## CHAPTER FIVE

### CONCLUSION AND RECOMMENDATIONS

#### 5.1 Introduction

This chapter presents the conclusions on the educational needs and assets of HBC-givers for home-bound chronic patients and recommendations based on the research question and findings of this study. These conclusions and recommendations may be useful to HBC organisations as well as the DoH and DSD.

The assumptions of this study are that HBC-givers are inadequately qualified due to a lack of relevant adequate training programmes, administration and managerial experience, monitoring and support as well as funds and resources.

#### 5.2 Conclusions

The aim of this study is to explore the educational needs and assets of home-based caregivers for home-bound chronic patients at Kgotlelelang Basadi HBC Centre in Limpopo. Research revealed that the HBC-givers at the centre have educational needs but also possess some assets that may enable them to effectively offer caring services.

##### 5.2.1 Educational needs

The following are the educational needs of the Kgotlelelang Basadi HBC Centre, based on the findings and analysis of this research.

- ***Caregivers' age and gender***

Three out of the 20 caregivers, including the manager, coordinator and finance officer, need to retire, bearing the fact in mind that they may not be able to cope as caregivers for they have to walk long distances between patients' homes. Other caregivers aged 36 years and upwards are often excluded from training programmes since some training providers focus on the training of young people. An example (presented in

Chapter four) is the Phelophepha Healthcare Train Project which trains caregivers younger than 35 years, for which only two caregivers from Kgotlelelang Basadi HBC Centre qualified. However, young people are not interested to join HBC, for caregivers only receive small stipends and no salaries.

The Kgotlelelang Basadi HBC Centre has only one male caregiver. This is probably due to the tradition that caring for the sick is dominated by females. In addition, HBC is mainly offered by volunteers who only receive small stipends, while men need proper salaries to provide for their families.

- ***Educational level of home-based caregivers***

Research has revealed that some caregivers have a very low literacy level due to the fact that they dropped out of school while still in the lower grades. Such caregivers are mainly illiterate and cannot read or understand training manuals, medication dosage and side effects. In addition, some caregivers are even unable to complete their contract forms. From this evidence it is clear that caregivers need to be better educated, or rather have passed Grade 12 to be capable of being trained or even further their health studies to be able to offer quality HBC. Low level education may compromise HBC services, both in health care and management.

- ***Adequate qualifications***

No specific qualifications are required to become an HBC-giver other than volunteering their services, some literacy, and personality traits such as respect, and being able to keep secrets since they deal with confidential issues. There are different categories of HBC services to be offered by HBC-givers as stipulated by the South African DSD's framework for HCBC and DSD support programme (2012:21). These include home visits, basic nursing care, performing house chores where necessary, provide basic counselling and information, education and communication, referrals, provision of treatment support, psychosocial support, prevention and awareness education capacity building and poverty alleviation.

Most of these categories need qualified people to perform such activities effectively. Based on the research findings, one can conclude that the caregivers do not possess adequate health care qualifications.

- ***Training programmes***

From the findings in this research one can conclude that the manager, coordinator, finance officer and caregivers are not well trained in their respective roles as providers of HBC services to home-bound chronic patients. Different caregivers were trained in different programmes, e.g two caregivers received training in HIV/AIDS care, and only one received training in counselling. Even though these training programmes are relevant, it is apparent that they are inadequate. Training programmes were short of duration but covered a large scope of information which, according to the respondents, was too much for them to grasp within such a short time. Some training programmes awarded certificates but seemed worthless since they indicate that training was offered for one day only. None of the above factors are conducive to motivate the caregivers.

The caregivers do not possess adequate knowledge and skills on the prevention and care of different diseases. The fact that the DoH instructed caregivers not to touch, feed, or turn their bed-ridden patients, perform house chores, or dress patients' wounds, proves that the DoH is aware of their inadequate training and the dangers linked to it. The only duties they are entrusted with include monitoring the administration of patients' medication and lay counselling. The research has shown that even these duties are not properly executed due to the caregivers' insufficient knowledge and poor training concerning medication and modest counselling skills.

- ***Administration and managerial experience***

According to the findings, caregivers do not possess the necessary administration or managerial skills. Some caregivers do not visit their patients on a regular basis but instead complete their record forms and even forge the patient's signature. According to these facts, it is clear that the manager is unable to direct and control the caregivers' services by supervising them, and therefore feels that they do not cooperate with her but rather defy her authority.

In their turn, the caregivers complain that the manager takes decisions without consulting them. The board of directors do not seem to know their roles and responsibilities since they interfere with the organisation's programmes and also argue about the funds and patients' food parcels. This all proves that the manager, board members and caregivers all lack managerial and problem solving skills.

- ***Monitoring and support***

The DoH, as major stakeholder, does not thoroughly monitor the services of the organisation, especially that of the caregivers who reportedly neglect their duties by not visiting patients as they are supposed to do. The DoH only relies on the written records compiled by the coordinator and the manager in securing funds from the DoH and other funders, like the National Lottery. The manager and the coordinator do not monitor the activities of caregivers.

Support and intervention can only be effective if there is monitoring and evaluation. Without monitoring, challenges will not be identified. The research has shown that monitoring and support is inadequate and not properly executed.

- ***Finances***

Being able to manage and secure funding is an asset. However, the organisation experiences financial problems due to the DoH's delayed deposits as well as the board members who do not sign stipend cheques in time.

The stipends, however, is insufficient, considering the nature of the caregivers' work, notwithstanding the fact that the HBC-givers of the centre are not much at risk due to being prohibited to touch their patients. Nevertheless, they walk many kilometres a day when visiting patients. They are also not safe when heading for the centre to submit their weekly patient reports since they have to walk for two to three kilometres through the countryside.

Since it is not certain whether the National Lottery will continue funding the project, the organisation urgently needs to invest in fundraising projects to initiate some income to sustain the organisation. They will also have to submit a proper proposal to their funder. It is a problem though, that the caregivers have no fundraising skills.

- ***Infrastructure***

The Kgotlelelang Basadi HBC Centre does not own any buildings. They presently occupy a dilapidated old bakery with no electricity or security. Their electronic equipment, such as computers and printers, and filing cabinets are stored and used in

a small and congested room volunteered by the clinic, which is approximately two kilometres from their present locality. Operating from two different venues which are far apart from each other hampers the smooth running of the organisation's activities.

- ***Equipment and facilities***

One can conclude that the organisation does not have sufficient equipment and facilities. However, the DoH provided them with two laptops, a computer and a printer which, according to the manager, are insufficient, for she anticipates that future caregivers will be computer literate. The furniture is also not sufficient.

- ***Other health care resources***

Although the clinic supplies the organisation with health care resources such as latex gloves, disposable nappies, bandages, anti-bacterial solutions, masks, and so forth, supplies always run short. For this, the Department of Health is to blame.

One can assume that the lack of protective gear puts caregivers, patients and their families at risk of becoming infected with different diseases. The safety and protection of the patients and their families are compromised since caregivers said they only distribute resources to the patients as they are not allowed to come into contact with them. Notwithstanding, caregivers sometimes come into contact with chronically ill and bed-ridden people with no proper care often living with small children or elderly people.

## **5.2.2 Educational assets**

The following are the educational assets of the Kgotlelelang Basadi HBC Centre which are obtained from the findings and analysis of this research.

- ***Age and gender of caregivers***

More than 50% of the caregivers' ages range between 34 and 49, which, according to the researcher, favours them in terms of age, for they can still continue for many years to offer their care to home-bound chronic patients. In contrast to older people finding it difficult to study further, it is easier for younger people; they can even register at an ABET centre to improve their educational standard.



- ***Educational level of HBC-givers***

The research revealed that only five caregivers out of 20 (which include the manager, coordinator and finance officer) had passed Grade 12. The remaining 15 dropped out of school between grades 8 and 11. It is evident that all the caregivers are literate to some extent, which is an asset to the centre, for at least they are able to read and write.

Kgotlelelang Basadi HBC-givers currently do not have relevant health care qualifications, but if they can attend various accredited courses, designed to be compatible with their level of education, they possess the potential of studying further. In addition, one of the villages, namely Thaba, serviced by Kgotlelelang Basadi HBC Centre, boasts an ABET centre where caregivers can register to improve their educational levels.

Another asset is the National Lottery which donated funds for further studies or to develop other skills such as computer literacy, mainly because of the two laptops and computer which are used exclusively by the manager and the finance officer since none of the caregivers are computer literate.

- ***Training programmes***

An asset to the caregivers is the clinic, where they can informally obtain information on diseases and medication, even though the information is limited with no formal workshops offered by the clinic. All of them have life experience, some as parents. Most of them are able to take care of ailing family members. The fact that they can read and write is also an asset, since it qualifies them for being trained. The training programmes offered to the caregivers are relevant even though these are inadequate. The DoH, DSD, Phelophepha Healthcare Train Project and NGOs, such as the National Lottery, also offer training programmes to caregivers.

- ***Administration and managerial experience***

Although their administration and managerial skills are not highly developed, the manager, coordinator, finance officer and caregivers keep records such as financial, patient and caregivers' profiles, an assets register and vehicle logbook. They keep records of the meetings and keep a minute book.

Financial records are well kept and reports are submitted to the various stakeholders like the DoH, DSD and the National Lottery.

- ***Monitoring and support***

Caregivers are not effectively monitored and supported by the clinic, the DoH or the DSD. However, the Polokwane municipality, councillors, traditional leaders, church leaders, patients' families, teachers and the community at large support them. Some community members and the ward councillor are also members of the board of directors.

- ***Finances***

At the time of this study, Kgotlelelang Basadi HBC Centre had no financial problems since they secured funding from the National Lottery and the DoH. The manager is proficient in writing proposals and compiling monthly reports in order to secure funding. The funds are competently managed by the manager and the finance officer even though the manager indicated that they are inadequately trained. The funds are strictly applied according to the instructions of the DoH and the National Lottery, and even though the board members and caregivers do not understand the procedures, the manager is able to abide by the instructions.

- ***Infrastructure***

Caregivers should, in terms of infrastructure, secure donors who can assist them in obtaining a building. Since they previously managed to secure funding from the National Lottery, it is evident that they are competent in writing proposals. It would not be a problem to acquire a building site or land, for the organisation has the full support of the traditional leaders from the four villages.

- ***Equipment and facilities***

The findings in this study show that the Kgotlelelang Basadi HBC Centre owns two laptops, a computer, a printer, three steel filing cabinets, two desks, eight office chairs, and 20 plastic chairs. The furniture, however, is not enough to accommodate all the people involved. More computers or laptops are needed so that all caregivers can have access to it.

Another asset is the organisation's vehicle, acquired with National Lottery funds. Although the caregivers complain that the vehicle is used exclusively by the manager and the coordinator, it helps in the running of managerial duties.

- ***Other resources***

The caregivers receive some health care resources and supplies from the DoH via the clinic. However, these don't seem to be sufficient, for they sometimes run out of such resources.

### **5.3 Recommendations**

The following recommendations are based on the findings, analysis and conclusions of this study.

#### **5.3.1 Caregivers' age and gender**

Research findings indicated that some organisations who offer health care training programmes require caregivers who are younger than 35 years. It is recommended that the Kgotlelelang Basadi HBC Centre should recruit young people who would be recommended for training in terms of age. Furthermore, young people are energetic and are more exposed to new technology than the older people.

#### **5.3.2 Educational level of home-based caregivers**

It is recommended that the Kgotlelelang Basadi HBC-givers improve their educational levels by enrolling at ABET centres and other institutions. Caregivers should at least pass Grade 12 in order to study further at tertiary institutions. Improving educational levels would enable caregivers to read and understand facts on different health conditions, including management, treatment and prevention. High educational levels would also provide them with opportunities to learn and use new technological devices. Training manuals, report writing and completing various forms also require a person who has passed a higher grade, for they can easily grasp what they are being taught.

### **5.3.3 Adequate qualifications**

Each post should meet the purpose of certain qualification requirements. An application to become a caregiver should be accompanied by a curriculum vitae and proof of qualifications. Since HBC-givers provide an essential and sensitive service, it is recommended that education authorities should initiate a health care qualification which should be an entry level for HBC. Lack of adequate qualifications may lead to caregivers being undermined and degraded by community members as people with no qualifications. Qualified caregivers should become permanently employed and receive a salary, not a stipend.

### **5.3.4 Training programmes**

HBC-givers should be well trained and well informed to offer quality patient care and to disseminate their acquired knowledge to patients and their families. Continuous training would keep caregivers abreast of new developments in medicine, treatment of different conditions and technology. Training programmes should include both theoretical and practical work, as well as computer literacy, fundraising, and counselling skills. Both the manager and the coordinator need to be trained in monitoring and evaluation skills.

The duration of training programmes should be sufficient depending on the scope of the course in order for the caregivers to grasp the content. Needs assessment on caregivers is also essential before planning training programmes. Certificates should be awarded to the trainees as motivation and proof of study.

### **5.3.5 Administration and managerial experience**

Caregivers should be equipped with administration and managerial knowledge and skills to assist in the operations of the organisation. When selecting a manager, coordinator or finance officer, the organisation has to seek someone who meets the requirements and experience. Furthermore, the DoH should continuously present administration and managerial training to HBC-givers so that they can effectively manage the organisation. It is also necessary for caregivers and board members to be clear about their functions and responsibilities, which will minimise conflict.

### **5.3.6 Monitoring and support**

HBC-givers' services should be monitored, evaluated and supported. Monitoring and support should be a continuous process in reviewing planned activities and ensuring that they are accomplished in such a way that the goals and objectives of an organisation are achieved. Both the DoH and DSD should provide monitoring and support to the organisation's management as well as the caregivers to establish whether they are still on course. The two departments should further examine caregivers at their patients' homes in order to establish whether they are executing their duties properly. Departmental officials should conduct door-to-door visits to clearly understand and experience the conditions under which caregivers are working. After monitoring and evaluation of the entire organisation, support should be offered in the form of applicable workshops and training programmes. The manager and coordinator should monitor the caregivers' activities.

Furthermore, the organisation should always maintain sound relationships with the community, schools, traditional leaders, the churches and other community organisations so that they can secure support from them.

### **5.3.7 Finances**

It was concluded that the Kgotlelelang Basadi HBC Centre's finances are insufficient. The organisation needs to secure donors to supplement the funding from the DoH. They should also become involved in fundraising. Moreover, the DoH and EPWP under the Department of Works should increase the caregivers' small stipends. Caregivers should actually be permanently employed and receive salaries. The DoH and EPWP should timely deposit funds for the salaries and stipends of the organisation's members.

### **5.3.8 Infrastructure**

A permanent building is needed, large enough to accommodate all the organisation's resources and activities, offices for the members, supplied with electricity. The building should be secured with a fence. The Kgotlelelang Basadi HBC Centre should

approach local traditional leaders and request a site or space where the building can be erected. Donors could be approached to erect the building and the fence.

### **5.3.9 Equipment and facilities**

The centre should approach private companies and other organisations for donations. Such companies can donate new or used equipment to the organisation.

### **5.3.10 Other health care resources**

The DoH, via the clinic, should earnestly, without failure, attempt to supply HBC-givers with sufficient resources to properly care for home-bound patients. It is also necessary for HBC-givers to apply for donations of resources from other companies. This will include *inter alia* latex gloves, cotton wool, bandages, anti-bacterial solutions and so forth, since the clinic sometimes runs out of such health care resources.

## **5.4 Recommendations for further study**

This study focussed on the educational needs and assets of HBC-givers at the Kgotlelelang Basadi HBC Centre which is based in a rural area characterised by poverty, a high unemployment rate and low literacy level. It is recommended that further studies be conducted on the educational needs and assets of HBC-givers in urban areas, which would provide good material for comparison. Other research can be conducted on the effectiveness of the curriculum in place for HBC-givers.

## **5.5 Conclusion**

This chapter presented conclusions and recommendations on the educational needs and assets of HBC-givers at the Kgotlelelang Basadi HBC Centre. Although the centre has assets that can enable them to provide quality care, it faces serious educational challenges that should be addressed as soon as possible.

The researcher believes that her recommendations will not only assist the providers of HBC, but also their patients and their families, including the broader community.

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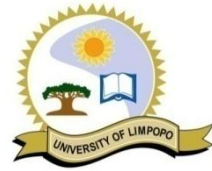
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## APPENDIX 1a

### LETTER OF CONSENT: UNIVERSITY OF LIMPOPO



# UNIVERSITY OF LIMPOPO Turfloop Campus



*Education Studies Department  
Community and Continuing Education Unit*

Private Bag X1106, SOVENGA 0727

Tel: +27 15 268 2961  
Fax: +27 15 268 2965  
e-mail: [phuti.moloko@ul.ac.za](mailto:phuti.moloko@ul.ac.za)

## **TO WHOM IT MAY CONCERN**

---

### **CONFIRMATION OF REGISTRATION AS POSTGRADUATE STUDENT – ACCESS TO YOUR INSTITUTION FOR RESEARCH PURPOSES**

This is to certify that **Ms Chuene MD** Student Number **201211472** is a registered postgraduate Master of Education (Adult Education) student at the University of Limpopo. She is currently busy with her research studies which require, among others, access and visits to your institution for research purposes. May she be kindly assisted as she requests.

Thank you in anticipation

Sincerely

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**Ms P D Moloko**  
**Supervisor: Community and Continuing Education Unit**

## APPENDIX 1b

### LETTER OF CONSENT: UNIVERSITY OF LIMPOPO



# UNIVERSITY OF LIMPOPO Turfloop Campus



*Education Studies Department  
Community and Continuing Education Unit*

Private Bag X1106, SOVENGA 0727

Tel: +27 15 268 2961  
Fax: +27 15 268 2965  
e-mail: [phuti.moloko@ul.ac.za](mailto:phuti.moloko@ul.ac.za)

## **TO WHOM IT MAY CONCERN**

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### **CONFIRMATION OF REGISTRATION AS POSTGRADUATE STUDENT – ACCESS TO THE UNIVERSITY LIBRARY DURING HOLIDAYS**

This is to certify that **Ms Chuene MD** Student Number **201211472** is a registered postgraduate Master of Education (Adult Education) student at the University of Limpopo. She is currently busy with her research studies which require, among others, visits and use of the library facilities during holidays. May she be kindly assisted as she requests.

Thank you in anticipation

Sincerely

---

**Ms P D Moloko**  
**Supervisor: Community and Continuing Education Unit**

**APPENDIX 2**

**LETTER OF CONSENT: KGOTLELELANG BASADI HOME-BASED CARE CENTRE**

**KGOTLELELANG BASADI HOME BASED CARE**

Stand No.130  
NPO Number:032-527

Contact Person: L.M. MASHAPHU  
Contact No: 079 8022 412



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*Care of Life & Environment*

**ACCEPTANCE LETTER**

*We As Kgotlelelang Basadi Home Based We Accept Mrs Chuene DM Id No 6503230590082 Student 201211472*

*Was Doing Research In Our Organization According to university of limpopo.*

*Hoping that the matter will be treated with respect it deserved*

*Yours faithfyllly*

*Mr. M. S. D. M. ....*

**APPENDIX 3  
CONSENT FORM**

**Research study: Educational needs and assets of home-based caregivers for home-bound chronic patients at Kgotlelelang Basadi Home-based Care Centre in the Capricorn district, Limpopo province.**

I.....

hereby give consent freely and without coercion to participate in the study entitled **Educational needs and assets of home-based caregivers for home-bound chronic patients at Kgotlelelang Basadi Home-based Care Centre in the Capricorn district, Limpopo province.**

My role in the study has been clearly explained to me by the researcher. My input will not in any way be linked to me personally and my right to confidentiality will be protected at all times. I understand that at any given point during this study I may withdraw if I so wish.

Name.....

Signature.....

Date.....

My name is Dayce Makakole Chuene. I am a Masters student in Community and Continuing Education in the Faculty of Humanities, in the School of Education at the University of Limpopo. I am currently conducting research on the educational needs and assets of home-based caregivers at the Kgotlelelang Basadi Home-based Care Centre.

I humbly request your participation in the research. Your participation will be voluntary, and your responses will be kept confidential between me and you.

I will share the findings with you after the research.

Signature.....

Date.....

**APPENDIX 4  
CONSENT FORM AND INTERVIEW GUIDE FOR THE MANAGER AND  
COORDINATOR**

**CONSENT FORM**

**Research study: Educational needs and assets of home-based caregivers for home-bound chronic patients at the Kgotlelelang Basadi Home-based Care Centre in the Capricorn district, Limpopo province.**

I.....

hereby give consent freely and without coercion to participate in the study entitled **Educational needs and assets of home-based caregivers for home-bound chronic patients at the Kgotlelelang Basadi Home-based Care Centre in the Capricorn district, Limpopo province.**

My role in the study has been clearly explained to me by the researcher. My input will not in any way be linked to me personally and my right to confidentiality will be protected at all times. I understand that at any given point during this study I may withdraw if I so wish.

Name.....

Signature.....

Date.....

**Facts and figures**

1. When did Kgotlelelang Basadi Home-based care start?
2. How many caregivers does the organisation have?
3. How many males and how many female are there in your organisation?
4. What are their ages?
5. What are the aims and objectives of your organisation?
6. Which services are offered by your organisation?
7. Is the community aware of the services you are offering?
8. How do you market this organisation to the community?
9. When were you appointed as the manager / coordinator of this organisation?
10. What are your main duties and responsibilities as manager / coordinator?
11. What are the opening hours of the centre? (day and time).
12. How many villages are served by your organisation, and what are their names?



13. What encourages you to be a caregiver?
14. How important are your services to the community?
15. What is your view on home-based care?
16. Do you think it is worth to exist?
17. How do you recruit caregivers?
18. What kind of personality is needed to be a caregiver?

### **Adequate Qualifications**

1. Which qualifications are needed to be a caregiver?
2. What is the level of literacy of a caregiver in this organisation?
3. What are the highest and lowest standards passed by the caregivers?
4. Do all caregivers in the organisation have adequate qualifications?
5. If not, what do you think is needed to be qualified?
6. How do you screen or conduct interviews for the job?

### **Training programmes**

1. Did you receive any educational health care training?
2. If yes, was the training adequate?
3. What was the duration of the educational health care services training?
4. Who conducted the training?
5. Did the training meet your educational needs?
6. How often are you engaged in educational training to improve your knowledge and skills?
7. Do you receive any certificates or evidence of attendance after training?
8. What are the benefits of such trainings?
9. Do you offer any training to the community and patients?
10. If yes, which kind of training do you offer them?
11. If no, what is your view about offering training to the community and patients?

### **Administration and managerial experience**

1. How do you manage this organisation?
2. Does the organisation have a board of directors?
3. If yes, how were they elected and what are their duties?
4. What is your day-to-day programme?
5. How do you keep records of the caregivers and their services?
6. How do you keep records of patients?
7. Do you convene meetings?
8. If yes, how often?
9. Do you record minutes of the meeting?
10. Do you have an assets register?
11. If yes, how do you control it; and if no, what is your view about it?
12. How do you manage the funds of the organisation?
13. What are you conditions of service and that of the caregivers?

### **Monitoring and support**

1. Under which government institution is your organisation placed?
2. Does the said institution monitor and evaluate your services?
3. How are the services of this organisation evaluated and monitored?
4. Who conduct monitoring?
5. What is your view on monitoring and evaluation?
6. Does your organisation receive any support?
7. If yes, how is the support offered?
8. Who offers the support?
9. If no, do you think you need support to sustain this organisation?

### **Funds and resources**

1. Does the organisation receive any funds?
2. If yes, who is funding the organisation?
3. Are the funds sufficient?
4. If no, how do you generate funds to add on what you are receiving?
5. Do you raise funds?
6. If yes, how do you fundraise?
7. If no, what is your view on fundraising in your organisation?
8. Do you get paid for your services?
9. If yes, who is responsible for your salary?
10. Which resources does your organisation have?
11. Are the resources relevant and adequate?
12. How do you ensure that the organisation has resources?

## APPENDIX 5

### CONSENT FORM AND INTERVIEW GUIDE FOR HOME-BOUND CHRONIC PATIENTS

#### CONSENT FORM

**Research study: Educational needs and assets of home-based caregivers for home-bound chronic patients at the Kgotlelelang Basadi Home-based Care Centre in the Capricorn district, Limpopo province.**

I.....

hereby give consent freely and without coercion to participate in the study entitled **Educational needs and assets of home-based caregivers for home-bound chronic patients at the Kgotlelelang Basadi Home-based Care Centre in the Capricorn district, Limpopo province.**

My role in the study has been clearly explained to me by the researcher. My input will not in any way be linked to me personally and my right to confidentiality will be protected at all times. I understand that at any given point during this study I may withdraw if I so wish.

Name.....

Signature.....

Date.....

1. How did it happen that you are being cared for by Kgotlelelang Basadi HBC-givers?
2. Do you and your family receive any training on how to take care of yourself?
3. How regularly do the caregivers visit you?
4. How do the caregivers start their day when caring for you?
5. What are the day-to-day duties of the caregivers in your home?
6. How long do they take when visiting you?
7. What are the attitude and behaviour of the caregivers?
8. How do you perceive the work of the caregivers?
9. Is HBC worth existing?

## **APPENDIX 6**

### **INTERVIEW GUIDE FOR HOME-BASED CAREGIVERS**

#### **Adequate qualifications and relevant training**

1. What encouraged you to become a caregiver?
2. Do you have qualifications as a caregiver? If yes, what are they? If no, what do you think should be done to qualify you?
3. Did you receive any educational health care training?
4. If yes, was training adequate?
5. What was the duration of the educational health care training?
6. If yes, was the training adequate?
7. What was the duration of the educational health care services training?
8. Who conducted the training?
9. Did the training meet your educational needs?
10. What are the benefits of such training?
11. Do you offer any training to the community and patients?
12. If yes, which kind of training do you offer them?
13. If no, what is your view about offering training to the community and patients?

#### **Administration and managerial experience**

1. What is your day-to-day programme?
2. How do you keep records of patients?
3. Do you convene meetings?
4. If yes, how often?
5. Do you record minutes of the meetings?
6. How do you manage funds of this organisation?
7. What are your conditions of service and that of the caregivers?
8. What is your view on HBC?
9. How important are your services to the community?

#### **Monitoring and support**

1. How are your service evaluated and monitored?
2. Who conduct monitoring?
3. What is your view on monitoring and evaluation?
4. Does your organisation receive any support?
5. If yes, how is the support offered?
6. Who offers the support?
7. If no, do you need support to sustain this organisation?

#### **Funds and resources**

1. Do you raise funds?
2. If yes, how do you fundraise?
3. If no, what is your view on fundraising in your organisation?
4. Do you get paid for your services?

5. If yes, who is responsible for your salary?
6. Which resources does your organisation have?
7. Are the resources relevant and adequate?
8. How do you ensure that the organisation has resources?

## **APPENDIX 7**

### **DOCUMENT ANALYSIS GUIDE**

In this phase I will go through written documents to gain insight on the qualifications, job descriptions, and how the organisation operates.

Documents to analyse:

- Vision and mission statement
- Constitution
- Policies
- Caregivers' profiles
- Employee register
- Time register
- Patients' records
- Financial records
- Asset register

## **APPENDIX 8**

### **OBSERVATION GUIDE**

In this phase I will conduct observation at the centre and at the patients' houses to observe how the caregivers carry out their duties.

Aspects to observe:

- Infrastructure
- Facilities
- Furniture
- Space
- Carers as they perform their service
- Training offered to caregivers, patients and their families, if any.

## APPENDIX 9 FOCUS GROUP INTERVIEW GUIDE

### Consent letter

**Research study: Educational needs and assets of home-based caregivers for home-bound chronic patients at the Kgotlelelang Basadi Home-based Care Centre in the Capricorn district, Limpopo province.**

I.....

hereby give consent freely and without coercion to participate in the study entitled **Educational needs and assets of home-based caregivers for home-bound chronic patients at the Kgotlelelang Basadi Home-based Care Centre in the Capricorn district, Limpopo province.**

My role in the study has been clearly explained to me by the researcher. My input will not in any way be linked to me personally and my right to confidentiality will be protected at all times. I understand that at any given point during this study I may withdraw if I so wish.

Name.....

Signature.....

Date.....

1. Describe your role as a caregiver.
2. What is a typical day like for you?
3. What are your challenges in being a caregiver?
4. What are your successes as HBC-giver?
5. What are the existing educational programmes of home-based caregivers and how relevant are those programmes?
6. What training needs do you have?
7. How are the caregivers' services monitored and evaluated?
8. What kind of support do the caregivers receive?
9. How do you get funds and resources?
10. What other resources and support do you need?



# **APPENDIX 10**

## **CONSENT FORM AND INTERVIEW GUIDE FOR THE PROFESSIONAL NURSE**

### **CONSENT FORM**

**Research study: Educational needs and assets of home-based caregivers for home-bound chronic patients at the Kgotlelelang Basadi Home-based Care Centre in the Capricorn district, Limpopo province.**

I.....

hereby give consent freely and without coercion to participate in the study entitled **Educational needs and assets of home-based caregivers for home-bound chronic patients at the Kgotlelelang Basadi Home-based Care Centre in the Capricorn district, Limpopo province.**

My role in the study has been clearly explained to me by the researcher. My input will not in any way linked to me personally and my right to confidentiality will be protected at all times. I understand that at any given point during this study I may withdraw if I so wish.

1. What is the relationship between the clinic and Kgotlelelang Basadi HBC Centre?
2. Does the clinic benefit from the HBC services? Substantiate your answer.
3. What is the day-to-day work of the caregivers in relation to your work as a clinic?
4. Does the clinic monitor and offer support to the Kgotlelelang Basadi HBC Centre?
5. Is the clinic involved in the management of the HBC? Substantiate your answer.
6. Do you know any challenges or successes of the organisation?
7. What is your view on HBC?
8. How do you perceive the work of the caregivers?
9. What do you think can be done to sustain the Kgotlelelang Basadi HBC Centre?

## APPENDIX 11

### DATA MATRIX

Data matrix based on interviews with the Kgotlelelang Basadi HBC Centre manager, coordinator, caregivers, patients and professional nurse.

<b>FACTS AND FIGURES - INCEPTION OF KGOTLELELANG BASADI HBC CENTRE</b>	
<b>Project manager</b>	The organisation was started on 30 April 2002 at Zoetfontein clinic under a tree, with only four volunteers from Makata, Thaba, Matobole and Mothiba without any stipends. Presently there are 17 caregivers who offer care to 78 patients. I was a caregiver and was appointed as manager in November 2012. The organisation operates from Monday - Friday from 08h00 to 16h00.
<b>Project coordinator</b>	Started in 2002 at Zoetfontein clinic under a tree by volunteers from Makata, Thaba, Matobole and Mothiba without any stipends. Presently there are 17 caregivers who offer care to 78 patients. I was a caregiver and was appointed as coordinator in October 2013. The organisation operates between Monday - Friday from 08h00 to 16h00.
<b>Caregivers</b>	The organisation started in 2002 at Zoetfontein clinic under a tree. We work from Monday to Friday, from 8h00 - 16h00. We are allocated patients from our villages. Presently the organisation has 78 registered patients.
<b>Professional nurse</b>	The organisation was started on 30 April 2002 at Zoetfontein clinic by a few women from Makata, Mothiba, Thaba and Matobole. They volunteered without stipends. They operate from Monday - Friday from 8h00 to 16h00.
<b>Patients</b>	-
<b>AIMS AND OBJECTIVES</b>	
<b>Project manager</b>	To offer care and support to patients with different conditions and to reduce the high rate of HIV/AIDS.
<b>Project coordinator</b>	To offer care and support to patients with different conditions and to reduce the high rate of HIV/AIDS.
<b>Caregivers</b>	To offer care and support to patients with different conditions and to reduce the high rate of HIV/AIDS.

<b>Professional nurse</b>	To offer care and support to patients suffering from various diseases. To help and monitor patients as they take medication so that they don't make mistakes.
<b>Patients</b>	-

### **THE ROLE OF CAREGIVERS, MANAGER, COORDINATOR AND PROFESSIONAL NURSE IN HBC**

<b>Project manager</b>	I manage the whole organisation, from finances to caregivers' activities, keep records, write and submit reports, and write proposals for the application of funds. Organise awareness campaigns.
<b>Project coordinator</b>	I keep records of patients and caregivers and help in organising awareness campaigns.
<b>Caretakers</b>	Take care of patients at their homes by monitoring them as they take their medication and also offer counselling to them.
<b>Professional nurse</b>	I allocate patients to caregivers and guide them on how to care for those patients.
<b>Patients</b>	-

### **WHAT MOTIVATED YOU TO BECOME A CAREGIVER?**

<b>Project manager</b>	To give support to patients who have nobody who can help them.
<b>Project coordinator</b>	I want to help the community by taking care of ailing people, especially those who live with AIDS.
<b>Caretakers</b>	We are not happy when we see ailing people defaulting for they do not have anyone to help them. Besides we are unemployed, so caring for the ill keep us busy.
<b>Professional nurse</b>	-
<b>Patients</b>	-

<b>DO YOU THINK HBC IS WORTH EXISTING?</b>	
<b>Project manager</b>	Yes, some families are not happy when the patients (family members) are hospitalised, so they appreciate HBC.
<b>Project coordinator</b>	Yes, the community and the patients' families are relieved because HBC reduces the spread of diseases through campaigns on prevention and care.
<b>Caretakers</b>	Yes, some patients are discharged from hospital whilst they are still ill and do not have relatives who can take care of them.
<b>Professional nurse</b>	Yes, HBC reduces hospitalisation of patients and defaulters.
<b>Patients</b>	Yes, the caregivers take care of us. They monitor and motivate us to take our medication.
<b>THE ROLE OF CAREGIVERS</b>	
<b>Project manager</b>	To promote and maintain the health of a patient, promote and maintain the patient's hygiene, monitor the patient with regard to treatment, care for the dying patient, offer health education to the community, keep records of what he/she does every day, file and submit reports to the coordinator every Friday, attend meetings with management and clinic staff.
<b>Project coordinator</b>	To promote and maintain the health of patients, promote and maintain their hygiene, monitor the patient with regard to treatment, care for the dying patient, offer health education to the community, keep records of what he/she does every day, receive file and reports submitted to me every Friday, attend meetings with management and clinic staff.
<b>Caretakers</b>	We maintain the health of patients, promote and maintain their hygiene, monitor them with regard to treatment, care for the dying, offer health education to the community, keep records of what he/she does every day, file and submit reports to the coordinator every Friday, attend meetings with management and clinic staff.
<b>Professional nurse</b>	-
<b>Patients</b>	-

### CAREGIVERS' AGE AND GENDER INCLUDING MANAGEMENT

<b>Project manager</b>	19 females and one male. Representative ages: 34-39 yrs = 5; 40-49 yrs = 8; 52-56 yrs = 3; 64 yrs = 1
<b>Project coordinator</b>	19 females and one male. Representative ages: 34-39 yrs = 5; 40-49 yrs = 8; 52-56 yrs = 3; 64 yrs = 1
<b>Caretakers</b>	-
<b>Professional nurse</b>	-
<b>Patients</b>	-

### EDUCATIONAL LEVEL OF HBC-GIVERS

<b>Project manager</b>	Not all caregivers received tertiary education except me and the finance officer; only three passed Grade 12, four passed Grade 11, four passed Grade 10, five passed Grade 9, and two passed Grade 8. Young educated people have no interest in joining the organisation as there is no salary. All caregivers are literate though some have a low literacy level, which has a negative effect on the organisation as it affects some activities of the organisation like report writing and completing contract forms. There is an ABET centre at Thaba village where caregivers can enrol to improve their educational levels, but they don't seem interested. The National Lottery allocated development funds for each of us to study further or improve our skills. Each caregiver is allocated R3000 for that purpose.
<b>Project coordinator</b>	Not all caregivers have tertiary qualifications except me and the finance officer. Only three passed Grade 12, four passed Grade 11, four passed Grade 10, five passed Grade 9, and two passed Grade 8.
<b>Caregivers</b>	-
<b>Professional nurse</b>	-
<b>Patients</b>	-

### ADEQUATE QUALIFICATIONS

<b>Project manager</b>	The caregivers do not have adequate qualifications necessary to be a caregiver. Even I, as manager, the coordinator, and the finance officer do not have adequate managerial and financial qualifications. There is no screening or interviews for caregivers: an interest to volunteer and a good personality are the only traits necessary.
<b>Project coordinator</b>	Qualifications are not needed. Only willingness to volunteer, respect, cleanliness, and the ability to keep secrets are considered.
<b>Caretakers</b>	We don't have any qualifications and they are not required to be a caregiver. We were not interviewed. One just indicates that she/he wants to volunteer to be a caregiver.
<b>Professional nurse</b>	-
<b>Patients</b>	-

### ADEQUATE RELEVANT TRAINING PROGRAMMES

<b>Project manager</b>	Neither management nor the caregivers are adequately trained. We received training for two days on the management of funds and report writing. We often attend workshops that last only a few hours, e.g 2-6 hours, which I feel it is not enough, for we cover a lot of things that should be covered in 2-4 weeks. Caregivers are also not well trained. The duration of their training ranges from one day to two weeks. The Ancillary Health Care training took a year to complete and was offered in block sessions. We did not receive certificates. Caregivers attend different programmes; e.g four received training on TB, two on HIV/AIDS, ten on breastfeeding and so forth. The DoH and some NGOs offer such training. We should be thoroughly trained on financial management, counselling, office management and administration and basic computer skills. Training in different diseases should be offered continuously as there are new caregivers who join the organisation when others leave. The training is relevant but inadequate.
<b>Project coordinator</b>	We are not well trained. Even as a caregiver, I was not adequately trained. Training in different diseases should be offered continuously as new caregivers join the organisation when others leave. As coordinator, I received training for two days only, for which we did not receive certificates. We need training on all diseases to help in monitoring caregivers and helping one another. We should be thoroughly trained in financial management, counselling, office management and administration and basic computer skills.

<b>Caretakers</b>	We do not have sufficient knowledge regarding our work because we are not adequately trained. We receive training for one or two days on our work; training that should be done over some weeks or months. The only sufficient training was that of Ancillary Health Care which we attended in block sessions and took one year to complete. However, we did not receive certificates as proof of training. After training we write tests, and even though we pass, we don't receive certificates. We need certificates so that when we leave this organisation, and look elsewhere for employment we can attach it to our curriculum vitae. We need some intensive training on health care. I have five patients living with HIV/AIDS, but I was not trained on HIV/AIDS. The department should train us on all the diseases' management and prevention. The training we already received is relevant but inadequate.
<b>Professional nurse</b>	-
<b>Patients</b>	-
<b>ADMINISTRATION AND MANAGERIAL EXPERIENCE</b>	
<b>Project manager</b>	I manage all the activities of the organisation including the finances. I compile and submit monthly reports to the DoH and the National Lottery. I convene meetings with caregivers and board members respectively. The clinic allocates patients to caregivers according to their villages. According to the policy of the DoH, nurses should issue referral letters to caregivers indicating all medical information of the patient, but sometimes they allocate patients without referral letters. I experience some problems with some of the caregivers. They do not work according to the policy: some of them start to work late, and they do not attend meetings and campaigns. Some of them do not visit their patients but nevertheless complete the patient's record form as proof of a visit. Since I conduct door-to-door awareness, I find that some patients are not visited, but their patient monitoring forms are completed. They do not adhere to 8 hours as stipulated by the DoH. Caregivers do not listen to me. Even when I report back from meetings with the departments, they do not believe me. The organisation has a board of directors who monitor the activities of the organisation. The board members also create problems for they influence caregivers to defy me. They fight over the organisation's money. They want to be paid for being board members which is against the policy of the DoH. Sometimes we have to beg them to sign cheques for they sign them when they like, delaying our salaries and the caregivers' stipends.
<b>Project coordinator</b>	I compile the carers' weekly reports which they submit every Friday, update their profiles, keep patients' files, take minutes during meetings, organise awareness campaigns and door-to-door awareness. At the end of each month, before we can get paid, we compile and submit reports to the DoH. As management we experience problems with caregivers who do not want to comply with the policies of the organisation and that of the DoH. Some caregivers do not offer service to patients, but write reports which indicate that

	they visited the patients. We discovered that they forge patients' signatures because during our door-to-door campaigns, some patients tell us that they are not regularly visited by their caregivers. The caregivers do not believe us when we report back to them after workshops and meetings. Another problem that hampers the progress of the organisation is the board of directors who want to be paid for being board members. Sometimes they do not want to authorise and sign cheques.
<b>Caretakers</b>	The nurses at the clinic allocate patients to us, but the problem is that often they do not give us referral letters that state the medical condition of the patient and his/her medication. The nurses usually guide us on how and when the medication should be taken, although sometimes we do not receive guidance. We take care of patients, attend meetings, and participate in awareness campaigns. We submit weekly patient record forms to the coordinator on Fridays where we also report problems we encountered with patients and their families. We attend meetings with management every month, but we have problems with the manager as she does not want to listen to our opinions and views. She imposes decisions on us. Board members do not sign cheques for our stipends on time.
<b>Professional nurse</b>	We allocate patients to caregivers according to the villages where they reside. How-ever, we realise that some caregivers do not visit and care for patients regularly since we have patients who default in terms of their medication. Some caregivers do good work as their patients' health conditions improve. We also work with the HBC in organising and participating in awareness campaigns.
<b>Patients</b>	I am cared for by a caregiver from the Kgotlelelang Basadi HBC Centre. My care-giver visits me every workday of the week (Monday to Friday) and motivates me to take medication as prescribed by the nurses and the doctor. She makes sure that I take the medication at the same time. My caregiver does not visit me regularly.
<b>MONITORING AND SUPPORT</b>	
<b>Project manager</b>	Our services are monitored by the DoH Capricorn District. The district monitors and evaluates the administration and finances of the organisation. They visit us twice a year and offer support where necessary.
<b>Project coordinator</b>	The DoH monitors and evaluates our work. They visit us twice a year.
<b>Caretakers</b>	The manager and coordinator monitor our work. They check our reports and do door-to-door enquiries to find out if we visit and care for patients, but do not offer any support. Sometimes we report problems we encountered during our visit, e.g patients who refuse to take their medication or those who warn us not to come again, but do not receive any help. The clinic also does not offer any



	support. Sometimes we locate other patients as we move around the villages and bring them to the clinic where they are diagnosed and put on HBC without any guidance on the medical condition of the patient or the medication. We don't attend meetings with the nurses to discuss patients' progress and problems. We are exposed to situations that affect us emotionally, like dying patients, but do not receive counselling.
<b>Professional nurse</b>	The services of the Kgotlelelang Basadi HBC Centre are monitored by departmental officials from the DoH. The clinic does not monitor or evaluate the organisation's services but support them during awareness campaigns. We are not involved in the management of the organisation.
<b>Patients</b>	-
<b>FINANCES</b>	
<b>Project manager</b>	We depend on the funds from the DoH, but fortunately, for now, we secured funds from the National Lottery. We get salaries and stipends from both funders. Funding from the National Lottery assist us especially when the DoH funding is not processed in time. We submit proposals for funding for a period of three years. Currently we don't experience any financial problems, but I foresee some problems if the National Lottery may not approve our proposal for the next financial year. We never attempt to raise funds except sending proposals to companies.
<b>Project coordinator</b>	We depend on the funds from the DoH, but fortunately we secured funds from the National Lottery. We get salaries and stipends from both funders. Funds from the National Lottery assist us when money from the DoH is not processed in time. We submit proposals for funding for a period of three years. We experience financial problems because we have to hire a driver as the National Lottery funded the purchase of a vehicle.
<b>Caretakers</b>	We are getting small stipends of R1230 from the DoH and R1200 from the National Lottery. This is too little, considering the difficult and dangerous conditions we are working in, e.g some of us are threatened by patients, and are also traumatised by the patient's conditions.
<b>Professional nurse</b>	According to the information that we get from the manager, caregivers are not satisfied with the stipend of R1200 from the DoH. I fully agree with them since they do a lot of work under difficult conditions.
<b>Patients</b>	-

## OTHER RESOURCES AND EQUIPMENT

<b>Project manager</b>	We get resources such as latex gloves, bandages, gauze, anti-bacterial solution, cotton wool, disposable nappies and masks from Zoetfontein clinic which sometimes runs short of such resources. We do not fundraise to supplement what we get from the clinic. As for office equipment, we need more computers so that all caregivers will be able to operate them. At present we only have two laptops and one computer. Furniture is also insufficient. We need chairs, office cabinets, and desks.
<b>Project coordinator</b>	Zoetfontein clinic supplies resources such as latex gloves, bandages, gauze, anti-bacterial solution, cotton wool, disposable nappies and masks, but sometimes the clinic runs short of such resources. Lack of the above resources in the organisation may not hamper the caregivers' work because the DoH instructed them not to touch, bathe, or clean the rooms of patients. They only take the resources from the clinic and distribute them to patients and their families and monitor patients as they take their medication. We never fundraise to supplement the resources that we get from the clinic. As for office equipment, we need more computers so that all caregivers will be able to operate them. We only have two laptops and one computer. Furniture is also not sufficient. We need chairs, office cabinets, and tables.
<b>Caretakers</b>	We get resources such as latex gloves, bandages, gauze, anti-bacterial solution, cotton wool, disposable nappies and masks from Zoetfontein clinic which sometimes runs short of such resources. We are sometimes supplied with thermometers but we do not use them as we are not well trained. Though the DoH does not allow us to come in physical contact with patients, sometimes we find ourselves in a situation where we feel we are obliged to help patients who are unable to sit, so that they can sit in a position which they can be able to take medication. In such instances we find ourselves in danger as we do not have such resources. There is no fundraising. We rely on what we get from the clinic.
<b>Professional nurse</b>	-
<b>Patients</b>	Caregivers supply us with resources such as bandages, cotton wool, latex gloves and disposable nappies, but most of the time they say the clinic does not have such resources, so as such we have to buy or improvise by using plastic bags for gloves and disposable nappies.

## INFRASTRUCTURE

<b>Project manager</b>	Kgotlelelang Basadi HBC Centre does not own any buildings. We use an old bakery which does not have electricity or security. The building was vandalised as it was not used for many years. It once had electricity, but because it was not used and had no security, the electrical cables are
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	reportedly stolen. The clinic offered us a small room which we use as administration office. Caregivers report at the dilapidated building every Friday to submit weekly patient reports.
<b>Project coordinator</b>	Our organisation does not own any buildings. We use an old bakery which does not have electricity or security. The building was vandalised as it was not used for many years. The building once had electricity, but because it was not used and had no security, the electrical cables were stolen. The clinic offered us a small room which we use as administration office. Caregivers report at the dilapidated building every Friday to submit their weekly patient reports.
<b>Caretakers</b>	We do not have our own building. We use an old bakery which does not have electricity or security. The building was vandalised as it was not used for many years. It once had electricity, but because it was not used and had no security, the electrical cables were stolen. The clinic offered us a small room which we use as administration office. We report at the dilapidated building every Friday to submit our weekly patient reports.
<b>Professional nurse</b>	-
<b>Patients</b>	-