A review of studies on home-based care to determine implications for social innovation in Namibia.

A REVIEW OF STUDIES ON HOME-BASED CARE TO DETERMINE IMPLICATIONS FOR SOCIAL INNOVATION IN NAMIBIA

BY

LEENA JOOLOKENI KAVELA

(NAMIBIA)

MTECH COMPARATIVE LOCAL DEVELOPMENT

TSHWANE UNIVERSITY OF TECHNOLOGY

PRETORIA

OCTOBER 2016

Certification

This is to certify that research report titled **'A REVIEW OF STUDIES ON HOME-BASED CARE TO DETERMINE IMPLICATIONS FOR SOCIAL INNOVATION IN NAMIBIA**' was carried out by Leena Joolokeni Kavela, under my supervision.

DR. L Ndabeni

Supervisor **Date----------**

Declaration

I, Leena Joolokeni Kavela do hereby declare that this research report entitled '**A REVIEW OF STUDIES ON HOME-BASED CARE TO DETERMINE IMPLICATIONS FOR SOCIAL INNOVATION IN NAMIBIA'** is my own work and that has not been submitted for any degree in any University, and that all the sources I have quoted have been indicated and acknowledged by means of complete references.

Signature: [redacted] **Date** 31 October 2016

Dedication

This project is dedicated to all those who are genuinely committed to the positive improvement and support of HBC of terminally-ill people in Namibia. It is also dedicated to my Husband, Eino Appolos Kavela who spent all the time taking care of the house and the children. It is further dedicated to Leena, Tangi, Opolili, Opomanga and Opoeli. In addition, it is dedicated to my sisters Ester, Eunike, Ndinelao and brothers Leopord and Licius, they helped me a lot in my studies and contributed a lot to assist my husband in taking care of the children.

Acknowledgement

First I must give thanks to Almighty God for giving me the opportunity to participate in this course; the God who granted me the grace to commence and complete this course.

Since this project started till its completion, many individual people contributed a lot in terms of useful ideas, encouragement, suggestions, prayers, moral support and fruitful criticism in order for me to be able to complete this research report. I would like to thank and given sincere acknowledgement to the following people:

- My Supervisor, Dr. Lindile Ndabeni of the Tshwane University of Technology for guidance, encouragement and support since the commencement of the research proposal, through all the stages of the research process up to the end of of this research report.
- My husband Eino A. Kavela and our beloved sons Tangi, Opolili, Opomanga and our daughter Opoeli and my niece Leena for their love , motivation, support and encouragement since the start till the completion of the research report.
- My gratitude also goes to my sisters: Ester, Eunike, Ndinelao and brothers: Leopord, Licius and Charipo for their endless assistance and support.
- Mr. Lukas Sithole, senior administrator at Innovation Economic Research of Tshwane University of Technology for the assistance, advice and encouragement.
- Mr. Touchmore Chikarango for endless support, and assistance in editing throughout my studies till the completion of this research report.
- Professor, J. Kangira, University of Namibia, who is also assisting in this research report.

Abstract

The social and economic consequences of the HIV/AIDS epidemic has shown that the disease has placed a large burden on public health care facilities especially in most southern African countries where the effect of the pandemic has been observed through the diminished capacity of health sectors. This observation has brought into focus the need for an alternative form of health care, viz, home-based care (HBC) as a critical element of the national health care system. HBC provides a continuum of care for persons with chronic illness from a health care facility to the home care environment where the care focuses on the overall well-being of the patient (Compbell, et al., 2005; Mwinituo, 2006). It is for this reason that explored the evolution of the HBC system within the context of innovation system and as part of the health care system in Namibia.

The study was guided by the Local Innovation and Productive Systems (LIPS) methodology which provides an analytical framework for understanding the systemic and interactive processes that lead to social innovation (Lastres & Cassiolato, 2005). The available secondary literature was used in the analysis of the findings including the content of the study where a detailed and systematic examination of contents of a particular body of material for the purpose of identifying patterns, themes or biases (Leedy and Ormrod, 2005).

Findings showed that HBC emerged as a social response to challenges that were facing society with different actors such as family, volunteers, NGOs, clinics, and hospitals playing different roles in the delivery of HBC. Furthermore, findings indicate that as much as there are benefits derived from HBC, there are also challenges facing the HBC system of which some include the costs associated with the provision of HBC at the home level, inadequate medical facilities to

complement the efforts of HBC, poor infrastructure and socio-cultural issues that have threatened the sustainability of HBC programmes particularly in Namibia and Sub-Saharan Africa in general. From the findings, it was concluded that formal HBC programmes started earlier in the 1980s with the main the main actors consisting of families, community volunteers, NGOs and government health institutions fulfilling the psychological, emotional, religious and spiritual needs of a patient by the family and the health team. Finally, it was also concluded that the HBC system is readily available (family members and community volunteers are available) and is affordable for the family members and the government. Despite some benefits, it can be concluded that the HBC system has some challenges that include HIV-positive persons straining family's resources, exposure to risks of contracting HIV by caregivers, shortage of trained personnel to administer drugs, and poor coordination and collaboration between key stakeholders and other sectors working at community. Considering findings and conclusions from the study, it was recommended that HBC should be incorporated and Institutionalized into both formal and informal institutions that can play a critical role in the development of HBC.

Table of Contents

List of Tables

Acronyms and Abbreviations

AIDS:	Acquired Immune Deficiency Syndrome
CBHC:	Community Based Health Care
CBO:	Community Based Organisations
CHBC:	Community Home-based Care
CORPS:	Community`s Own Resource Persons
CSO:	Civil Society Organisations
FBO:	Faith Based Organisations
GDP:	Gross Domestic Product
GRN:	Government of the Republic of Namibia
HBC:	Home-Based Care
HIV:	Human Immunodeficiency Virus
LIPS:	Local Productive and Innovation Systems
MoHCW:	Ministry of Health and child Welfare
MOHSS:	Ministry of Health Social Services
MMM:	Make Mothers Matter
MTP:	Medium-Term Plan
NACP:	National AIDS Control Project
NANGOF:	Namibia Non-Governmental Organisations Forum
NDP:	Namibia Development Plan
NER:	North Eastern Region
NGO:	Non-Governmental Organisations
NPC:	National Planning Commission

NRCS:	Namibia Red Cross Society
PLWHA:	Person /People Living With HIV and AIDS
TB:	Tuberculosis
UNAIDS:	Joint United Nations Programme on HIV/ AIDS
UNDP:	United Nation Development Programme
UNICEF:	United Nations Children`s Fund
UNGASS:	United Nations General Assembly Special Session
UN:	United Nations
USAID:	States Agency for International Development
USA:	United States of America
VDC:	Village Development Committee
VHC:	Village Health Committee
WHO:	World Health Organisation
UNDP:	United Nation Development Programme

CHAPTER 1: INTRODUCTION

1.1 Introduction

The social and economic consequences of the HIV/AIDS epidemic show that the disease has placed a large burden on public health care facilities. For example, in Kenya it was observed that 50-60% of public hospital beds were occupied by HIV patients (Opiyo et al., 2008). Indeed, the effect of the pandemic has been observed through the diminished capacity of health sectors in many countries such as Tanzania, Kenya and South Africa. More specifically, in the situation of Namibia, the public health care system is characterised by weak infrastructure, spiralling health costs and insufficient resources, and the majority of Namibians cannot afford the drugs and transport costs of getting the HIV/AIDS patients regularly to and from hospitals (MOHSS and Macro International, 2007). This observation has brought into focus the need for an alternative form of health care, *viz*, home-based care (HBC) as a critical element of the national health care system.

The Word Health Organisation (WHO, 2006) defines home-based care (HBC) as the provision of health services by formal and informal caregivers in the patient`s home in order to promote, restore and maintain a person`s maximum level of comfort, function and health, including care, towards a dignified death. In Namibia, HBC and community based care include preventative, therapeutic, rehabilitative, long term maintenance and palliative care. Community based care is care that consumers can access nearest to their homes (MOHSS, 2007). It is argued that community based care responds to the needs of people and it encourages traditional community life and creates responsibilities (MOHSS, 2007). These patient- and family-centred approaches use the skills of interdisciplinary team members to improve a comprehensive continuum of care, including spiritual and emotional care (WHO,

2006). Moreover, HBC provides a continuum of care for persons with chronic illness from a health care facility to the home care environment. It is worth noting that HBC is often offered within a continuum of care that focuses on the overall well-being of the patient (Compbell, et al., 2005; Mwinituo, 2006). Consequently, in Namibia HBC has increasingly become a national policy priority. Indeed, in South Africa, it has been reported that average stay in hospital decreased from 14 days to 3.5 days when a referral to a HBC was made. However, the unintended consequences of HBC are that it has placed a heavy burden on affected families and communities (Ncama, 2005).

There exists a research lacuna in terms of examining innovations that are intended to improve HBC systems. Accordingly, the objective in this study is to review studies on home-based care systems in order to highlight implications for social innovation. More specifically, social innovations in home-based care comprise of social and adaptive solutions - including new ways of organising human resources, information, governance, and decision-making that allow for the improvement of home-based care system.

The study as a whole explores the evolution of the HBC system and the different kinds of HBC; it highlights the roles of different actors both formal and informal and their interactions in order to determine knowledge flows and boundaries of the system; and finally, it highlights the benefits, challenges and contradictions within the HBC system. In this study, home-based care systems are explored within the context of the national health care system in Namibia.

1.2 Socio-Economic Context of Namibia

This section focuses on the appropriateness of the study to its spatial, social and economic context. That is to say, the aim in this section is to expand our understanding of the context within which the study is undertaken and within which HBC occurs as the problems of HBC are often embedded in their context.

Namibia is located in the south-western part of Africa on the south-west Atlantic Coast of Africa, bordering Angola and Zambia in the north, Botswana in the east and South Africa in the south-east. Namibia has 14 administrative regions which are grouped together to form North, North-Central, Central and South regions. First, the Northern Region consists of Zambezi (which was called Caprivi), Kavango East, Kavango West, Oshikoto, Ohangwena, Oshana and Omusati. Second, the North-Central Region is made up of Kunene, Otjozondjupa and Omaheke. Third, the Central Region consists of Khomas - where the capital city, Windhoek, is located (National Planning Commission, 2011). Khomas is the largest economic region with an area size of 36,805km2 and a population of 340,900. It occupies 4.5% of the land area of Namibia and has the highest number of population in the country (National Planning Commission, 2001).

This region has well-developed economic, financial, and trade sectors and provides the better transportation infrastructure in the country. Last is the Southern Region, which consists of Erongo, Hardap and Karas regions (MOHSS, 2007). Overall, the country has one of the lowest population densities in the world with 1.5 persons per square metre (National Planning Commission, 2011).

Since independence in 1990, a lot of changes have taken place in Namibia. These include rapid influx of people into regions that have visible productive activities, especially Windhoek. The majority of the migrants often do not have employable skills. As a country, Namibia is classified as a low-middle income country which is heavily dependent on the extraction and processing of minerals for export (MOHSS, 2010). According to the 2011 survey, Namibia has an economic annual growth rate of 6.6 % (National Planning Commission, 2011). More importantly, the country has one of the highest Gini coefficients in the world (National Planning Commission, 2006). Namibia's Gini coefficient was estimated at 0.6 and provides a measure of income distribution across various segments of society in Namibia (MOHSS, 2010). Finally, this research recognises the challenge of varied spaces of social exclusion in Namibia and the need for inclusive development.

1.3 Evolution of Home-Based Care Systems

In looking at the evolution of HBC, Spier and Edwards (1990) argue that HBC programmes started in North America and Europe in the late 1980s, when it became clear that hospital care was too expensive and that families and other caregivers found it difficult to cope on their own due to the demanding nature of caring for PLWHA. In the United States, the Committee on National Strategy for AIDS concluded that if the care for terminally ill patients is to be both comprehensive and cost effective, it must be conducted as much as possible in the community, with hospitalization only when necessary. It stresses that the various requirements for the care of patients with symptomatic HIV infection or AIDS (community-based care, HBC, outpatient care and hospitalization) should be carefully coordinated and monitored (Committee on a National Strategy for AIDS, 1986). In the case of Norway, the emphasis in terms of home-based AIDS care is on domestic tasks such as cleaning, laundry

and shopping, while in USA home-based HIV/AIDS care is centred on problems in home maintenance, individual coping, nutrition, feeding and fatigue (Ncama, 2005).

In Brazil, the majority of PLWHA are registered in the public health system and are receiving treatment. Through the public health system, a network for diagnosis, prevention, treatment and follow-up was organised and currently includes 397 accredited hospitals, 79 day-care hospitals, 58 home-care centres and 422 outpatient facilities (Brazil, 2004). In Sao Paolo in Brazil, the Catholic nuns started Project Hope to provide support and care for families affected by AIDS, cancer and tuberculosis. The number of volunteers has increased to 100 volunteers who each give a few hours of their time per week. The volunteers each visit few families where parents are ill. They provide basic home basic care, counselling and help care for children. The project also looks after children once their parents have died. Sao Paolo home care service provides HBC and helps to set up support groups for terminally-ill patients and their families (Brazil, 2005).

The evolution of HBC, especially in Africa, has been due to various contextual factors. For example, HBC in Botswana has increased due to a move from hospital care to HBC because of the high increase in the number of terminally ill patients (Shalibu, 2006). In South Africa, the integrated community based model was developed in rural hospice in the mid-1990s to deal with the HIV/AIDS pandemic (Uys, 2003), while in Zimbabwe hospital services declined due to budget reductions. Finally, in Uganda the HBC programme also takes care of the children and families of people who are HIV positive (Campbell 2005).

In the case of Africa as a whole, HBC was launched during the late 1980s and early 1990s. This was when it became evident that other options of care were necessary to deal with

effects of terminal diseases such as cancer, HIV/AIDS and tuberculosis (WHO, 2006). According to Nnamdi-Okagbue (2006), in Sub-Saharan Africa and other developing countries, HBC programmes were developed as unsystematic and need-based efforts. These community home-based care programmes were mainly initiated by NGOs, CBOs, FBOs and concerned individuals.

Overall, HBC programmes can be grouped according to the service they render (service models) and their structure (structure models). The service model has two categories: home visiting and comprehensive HBC; whereas the structure model is composed of isolated, specialized or private as well as integrated or collaborative HBC agencies (Ncama, 2005).

At a psychological level, the fear of stigma and discrimination from doctors and nurses has caused terminally ill patients to choose HBC (MOHSS, 2009). Again, in Ghana the secrecy and stigma surrounding HIV/AIDS illness, cancer and tuberculosis posed a major barrier to the provision of HBC, especially for the patients but also for the carers (Radstake, 2005).

The cost, both direct (paying for transport) and indirect (time lost from work) associated with going to hospital regularly also means that being cared for at home is often an inevitability rather than a choice. However, HBC has its challenges. It tends to increase the involvement of the patients' families and communities in addressing the harsh realities of caring for the infected. Generally, family members are regarded as the primary caregivers (MOHSS, 2009). Their motivation to care for their loved ones who are ill is out of love and a sense of kinship (De Monchy, 2005). Indeed, the terminally-ill people normally need to be surrounded by those they are familiar with in a familiar environment. This affords them the control of reliving past memories and addressing unresolved issues in the familiarity of their homes.

A potential benefit of HBC is that the patients are surrounded by people they love and are familiar with. Furthermore, they are not exposed to hospital-based infectious diseases. As people with terminal illnesses generally spend their final moments at home, improving the quality of their care at home also removes the cost and distress of travelling to and from the hospital when they are at their weakest point. Furthermore, in being cared for at home, a person with HIV may be more ready to work or look after family members for short periods of time while the primary earners are at work. The time the family would otherwise use travelling to and from hospital can instead be spent on housework and looking after other family members. Expenditure on transport and hospital costs is also reduced (MOHSS, 2006; Crook, 2005).

In looking at the organisation of human resources within the HBC, Ogden, et al. (2006) assert that care for 90 per cent of illnesses may be provided for at home by untrained family members and associates. However, it must also be acknowledged that HBC often results from necessity rather than choice. This is when health care facilities are failing to cope with increased number of patients.

MOHSS (2010) indicates that effective HBC programmes include continuous support for the workers, support from local communities and integration within the existing health systems. However, one of the key factors that can be considered as a barrier to the achievement of the objectives of HBC is that most of the HBC, especially in Namibia, are often carried out by family members who have no contact with professional help and lack the necessary support. This means that infected people may be inadequately looked after despite the best efforts of their carers and families.

The challenges of HBC often stem from the lack of investment in the individuals and organisations that carry out the work (Catholic AIDS Action, 2005; Sartorie, 2006). It should also be remembered that HBC organisations are unable to attend to patients around the clock. Therefore, there are limitations on what they should be expected to do. Tasks like changing bandages and assisting with more frequent occurrences such as going to the toilet are mostly done by family members.

1.4 Background and Motivation

The Government of Namibia recognises that health is a fundamental human right of all Namibians and is committed to achieving health for all Namibians (Ministry of Health And Social Services, 2007). Despite the recognition, Namibia currently stands as one of the worst-affected countries in the world in terms of HIV and AIDS with an estimated 18.8% prevalence rate amongst pregnant women (Campbell & MacMillan, 2012). According to Uushona (2006), Namibia is a country with a high prevalence of HIV infection and many hospitals and health facilities around the country are experiencing social, economic and health care problems related to HIV/AIDS patients. The challenges faced by the formal health-care services in Namibia have led to the need to consider home based care as an option to cater for the needs of the HIV/AIDS, cancer and tuberculosis patients with the support of family members and communities (Uushona, 2006).

An increased number of patients living with cancer, HIV/AIDS and tuberculosis have constrained the health care services, with hospitals struggling to admit all very sick patients. Consequently, home based care (HBC) has increasingly evolved as an alternative solution to

this challenge. Accordingly, it is against this background that there is a need to undertake research on HBC systems and highlight implications for social innovation. Indeed, not much has been researched in terms of:

- Understanding social and economic benefits of HBC on the one hand, and challenges and contradictions of HBC policy on the other hand;
- Highlighting implications for social innovation as part of initiatives for improved HBC systems.

1.5 Problem Statement

Since 1986, when the first case of advanced human immunodeficiency virus (HIV) disease was diagnosed in Namibia, many challenges regarding infrastructure, facilities and logistics were encountered to fight against the disease (Republic of Namibia, 2006). The 2001 National Population Survey by the National Planning Commission (2001) predicted an increasing need for quality community home based care to support people on tuberculosis (TB) treatment, people living with HIV/AIDS and other clients with life–threatening illnesses such as an estimated 200,000 people who also need care and support provided beyond the family structures.

Sixteen years after independence in 2006, Namibia had a high prevalence of HIV infection and many hospitals and health facilities around the country were experiencing social, economic and health care problems related to HIV/AIDS, cancer and tuberculosis patients (Uushona, 2006). Due to problems and challenges related to HIV/AIDS, cancer and tuberculosis patients, Uushona (2006) further explained that the home based care option was seen as an alternative to cater for the needs of the terminally-ill patients with the support of

family members and communities. The Ministry of Health and Social Services recognised the key role that Community Home-based Care (CHBC) can provide for people with HIV (Human Immuno-deficiency Virus) and AIDS (Acquired Immuno-deficiency Syndrome) and other chronic and life–threatening illnesses, and affected family members, particularly children (Ministry of Health and Social Services, 2010). Therefore, this study explored HBC from the perspective of innovation systems and as part of the health care system in Namibia that highlights the social and economic issues that relate to HBC in the Namibian health care system.

1.6 Research Questions

This literature-based study is aimed at increasing our understanding of the HBC system in Namibia. Accordingly, the research questions guiding this study are:

- How did the HBC system evolve?
- What are the roles of different actors within the HBC system?
- What are the implications for social innovation?

1.7 Purpose of the Research

The purpose of this study is to explore HBC from the perspective of innovation systems and as part of the health care system in Namibia. The study will attempt to highlight the social and economic issues that relate to HBC in the Namibian health care system.

1.8 Research Objectives

The objective in this study is three-fold. First is to explore the evolution of the HBC system and the different kinds of HBC. Second is to examine the roles of different actors and their interactions in order to determine knowledge flows and boundaries of the system. Finally, it is to explore the benefits, challenges, and contradictions within the HBC system in order to determine implications for social innovation and improved social delivery of HBC.

1.9 Significance Of The Study

The significance of this research is two-fold. One is to highlight the different roles of actors, their interactions, knowledge flows, and organisation of human resources. Secondly, and equally important, the contribution of the study is in terms of highlighting implications for social innovation as part of national initiatives for improved HBC systems in Namibia.

1.10 Research Methodology

This section provides an overview of the research methodology and research design that was utilised for successful undertaking of this study. The study is a literature-based study. More specifically, the research is based on the study of available literature - both published and unpublished sources such as research reports, dissertations, government policies, books, and journals including those available from different websites on the internet.

As part of innovation studies, this research was guided by the Local Innovation and Productive Systems (LIPS) methodology which provides an analytical framework for

understanding the systemic and interactive processes that lead to social innovation (Lastres & Cassiolato, 2005). More specifically, social innovation refers to a process through which organisations incorporate knowledge in the production of goods or services that are new to them and which are geared to meet social needs. Social innovation derives from an interactive and transforming dynamic, developed with the participation of local actors and appropriated by them, representing solutions to social challenges and to the improvement of living conditions (Redesist, 2012).

The LIPS methodology pays specific attention to the dimensions of solutions to social challenges and to the improvement of living conditions (De Matos, Soares & Cassiolato, 2012).

According to De Matos, Soares, and Cassiolato (2012) the LIPS methodology pays specific attention to the following dimensions:

- Territorial dimension particularly with the need to contextualize the study within its geographical set-up.
- Diversity of activities undertaken by diverse economic, political and social actors.

One of the critical aspects of the study relates to our acknowledgement of the diversity of activities, actors such as families, community volunteers, NGOs as well as hospitals. More specifically, the diverse actors include families that provide care to the patients, community volunteers who give health educational awareness on how to prevent diseases, hospitals that provide services to the patients and NGOs that provide financial support.

- Tacit knowledge can be observed as non-codified, locally-specific knowledge that develops over time as a result of territorial proximity and/or cultural, social, and commercial identities.
- Interactive innovation and learning are regarded as the central focus of the analysis.
- Governance refers to different ways of coordination among actors influencing the process of decision-making and shaping of social innovations.
- Degree of being embedded means the degree of commitment and articulation of HBC actors.

The available secondary literature was used in the analysis of the findings including the content of the study. Leedy and Ormrod (2005) define content analysis as a detailed and systematic examination of contents of a particular body of material for the purpose of identifying patterns, themes or biases.

The study will be qualitative in nature. Qualitative research design suits studies where the researcher seeks to explore the meaning or describe human experiences such as grief, chronic conditions and pain (Neuman, 2006). This methodology is relevant to this study as it seeks to examine HBC in the particular context of Namibia. Indeed, Leedy and Ormrod (2005), highlight that the qualitative research design suits studies where the researcher describes the meaning and reveals the nature of certain situation or interpretation that enable the researcher to discover the problems that exist within a phenomenon.

1.11 Chapter Outline

Chapter 1: Introduction - The focus of this chapter is on the background to this research, the problem statement, purpose of the study, research question, research objectives, and the significance of the study. The chapter also presents a brief description of the research methodology and the research design that will be utilized in this study.

Chapter 2: Literature Review - This chapter reviews two kinds of literature. One relates to the general literature on home-based care in Namibia and internationally. Secondly, it examines a body of literature on innovation studies as an important theoretical framework for understanding and interpreting HBC systems in Namibia.

Chapter 3: Data Analysis and Presentation of Research Findings - This chapter highlights key findings made from the analysis of the available literature on HBC and innovation systems. The chapter also presents brief descriptions of the research design and techniques that will be used in data collection for the study. This chapter analyses the data collected for the study.

Chapter 4: Conclusion and Recommendations - This chapter provides the conclusion and recommendations, and highlights implications for social innovation. It also points to areas for possible future studies.

1.12 Conclusion

This chapter has outlined the Namibian socio-economic profile. The background to this research, the problem statement, purpose of the study, research questions, research objectives, and the significance of the study have also been presented. The chapter has also given a brief

description of the research methodology and the research design that has been utilised in this study. Finally, the research report as a whole will be organised into the following chapters:

CHAPTER 2: HOME-BASED CARE: A LITERATURE REVIEW

2.1 Introduction

The World Health Organisation defines home-based care (HBC) as the provision of health services by formal and informal caregivers in the patient`s home in order to promote, restore and maintain a person`s maximum level of comfort, function and health, including care towards a dignified death (WHO, 2006). Ncama and Young (2005; 2010) also define home-based care as any form of care given to sick people in their homes, which includes physical, psychosocial, palliative, and spiritual activities. Families are the central focus of HBC and form the basis of the HBC system.

HBC is often extended from the health care facility to the client's home through family involvement and community participation. Indeed, homes are places where people live and provide a source of support and care to individuals and families in need (Ncama, 2005). Given the centrality of the home in the HBC system, it is important to assess the suitability of the home environment to meet the needs and aspirations of the patients. More importantly, HBC can be seen as part of the care economy. In particular, the care economy relates to unremunerated work undertaken within the house. The unremunerated work ensures the physical, social, psychological maintenance and development of family members.

The objective in this chapter is to review the relevant literature on home-based care (HBC) to determine implications for policy development and social innovation. The chapter is structured into seven sections of material, namely: descriptive analysis of HBC, the evolution

of HBC, social and economic issues of HBC, benefits and challenges of HBC, models of HBC, and the experiences of HBC in selected countries.

2.2 Descriptive Analysis of Home-Based Care

The World Health Organisation defines home-based care as the provision of health services by formal and informal caregivers in the patient`s home in order to promote, restore and maintain a person`s maximum level of comfort, function and health, including care towards a dignified death (WHO, 2006). This definition puts emphasis on provision of health services at home by both formal and informal caregivers as opposed to hospital-based care where the health services are entirely provided by formal caregivers in a hospital. Ncama and Young (2010) also define home-based care as any form of care given to sick people in their homes, which includes physical, psychosocial, palliative, and spiritual activities. Home-based care can also be defined as the care of persons that is extended from the health facility to the patient's home through family participation and community involvement, and in collaboration with health care workers (Republic of Kenya, 2002).

Families are the central focus of HBC and form the basis of the HBC system. Indeed, homes are places where people live and provide a source of support and care to individuals and families in need (Ncama, 2005). As a comprehensive form of care, HBC includes clinical care, nursing care, palliative care, counselling and psycho-spiritual care and social support (Ncama, 2005). It is often extended from the health care facility to the client's home through family involvement and community participation. Given the centrality of the home in the HBC system, it is important to assess the suitability of the home environment to meet the needs and aspirations of the patients.

HBC is also considered as a component of a comprehensive continuum of treatment, prevention and support services to people living with HIV/AIDS (PLWHA), cancer and tuberculosis (UNGASS, 2006). More specifically, due to the increased number of HIV/AIDS patients, communities have been mobilised to provide care to the sick in their home and community (UNGASS, 2006). Therefore, the provision of HBC is regarded as an essential component of the continuum of care for persons living with HIV/AIDS and other terminal diseases (MOHSS, 2007). According to MOHSS (2007), HBC is aimed at:

- Facilitating the continuity of the patient's care from the health facility to the home and community;
- Promoting family and community awareness of disease prevention and care related to chronic illnesses;
- Empowering the patients, the family and the community with the knowledge and skills needed to ensure long-term care and support;
- Streamlining the patient referral from the institutions into the community and from the community to appropriate health and social welfare facilities;
- Facilitating quality homecare services; and,
- Mobilising resources necessary for sustainability of the HBC services.

In order to gain a clear understanding of the HBC system, a comparison can be drawn between home-based care and hospital-based care as shown in Table 2.1.

Table 2.1: Comparison Between Hospital-based Care and Home-based Care

Hospital-based Care	**Home-based Care**
High costs to set up and run.	Low cost in comparison to hospitals.
Focus of care is on the disease.	Focus is the whole person.
Quality of medical care is good.	Quality of medical care is good.
Non-medical care is not available.	Non-medical care is available.
Relationships exist with medical staff only.	The patient is part of a web of relationships including medical staff, volunteers, community, family and other HIV positive people.
Awareness and prevention are regarded as separate activities.	Awareness and prevention are integrated.
Patients are referred to outside organisations to access long-term, holistic care.	Patients are assisted to access hospital treatment when necessary.

Source: Beechey, 2004

2.3 The Evolution of Home-Based Care

The HBC programmes started in North America and Europe in the late 1980s, when it became clear that hospital care was too expensive and that families and other caregivers found it difficult to cope on their own with the demanding nature of caring for PLWHA (Spier and Edwards,1990). In the United States of America (USA), the Committee on National Strategy for AIDS concluded that if the care for HIV/AIDS patients was to be both comprehensive and cost effective, it must be conducted as much as possible in the

community, with hospitalisation only when necessary (Committee on National Strategy for AIDS, 1986).

Although HBC formally originated in USA, family care in Africa has long been part of life despite not being formalised (Uys, 2003). In Sub-Saharan Africa and other developing countries, HBC programmes were developed in an unsystematic way and based on need. This was when it became evident that other options of care were necessary to deal with the effects of HIV/AIDS, cancer and tuberculosis (WHO, 2006).

In the case of Africa, community-based care was mainly initiated by non-governmental organisations (NGOs), community-based organisations (CBOs), faith-based organisations (FBOs) and concerned individuals (Nnamndi-Okagbue, 2006). Accordingly, the HBC system was meant to be a support mechanism for the hospital-based care system, and PLWHA and their families. That is to say, the HBC was a way of empowering communities to respond to the impact of HIV/AIDS, cancer and tuberculosis (Young, 2010). Indeed, it has been indicated that up to 90% of illness care is provided for in the home environment (WHO, 2007).

A number of HBC programmes have been instituted in different parts of the world. These programmes are grouped according to the service they render (service models) and their structure models (Ncama, 2005). In particular, the service model has two categories *viz*, home visiting and comprehensive home-based care. By contrast, the structure model is composed of isolated, specialized, private as well as integrated or collaborative HBC agencies (Ncama, 2005).

The Namibian government recognised the need for HBC in the country as a way of caring for HIV/AIDS, cancer and tuberculosis patients (MOHSS, 2007). This form of HBC is considered as a more socially supportive system compared to hospital-based care. While the country recognised the importance of HBC, the relatives of sick patients particularly in the North Eastern regions of Namibia considered the hospital to be the best place where best care can be given to their sick relatives (UNICEF, 1998). What is worth noting is that HIV/AIDS patients who have been admitted to hospital tend to face a higher degree of discrimination and rejection than those who have been taken care of at home by their family members (UNICEF, 1998).

2.4 Models of Home-Based Care

The objective in this section is to examine a number of HBC models. These include home visiting based care, the comprehensive home-based care, the integrated and collaborative home-based care, the specialised or private home-based care and the informal home-based care.

First, home visiting based care relates to a situation where volunteers visit patients in their homes. In the course of their visit, volunteers also educate patients and their families about basic care (Akintola, 2004). This form of HBC also provides support with cooking, cleaning, errands, and patients are accompanied to health care facilities. Home visitors may also organise access to food parcels and other material support (Ncama, 2005). Furthermore, this model involves self-help projects among social groups such as church groups and other initiatives organised by NGOs and concerned individuals, especially retired nurses (Ncama, 2005). This model has no referral system in place.

Second, the comprehensive home-based care model provides various degrees of palliative care (Ncama, 2005). These programmes are run by established NGOs such as the Hospice Association of Southern Africa, Red Cross Societies, or church-linked groupings. It also provides training for caregivers including supportive counselling, cleaning and dressing wounds, oral hygiene and supervision of medication taking, necrotic wound care, pain management, and diagnosis of opportunistic infections (Ncama, 2005). Some comprehensive HBC programmes incorporate orphan care, social support, and income-generation activities (Rachlis, 2013).

Third, the integrated and collaborative home-based care links all services provided to the patients and their families in a continuum of care (Young, 2010). The objective in this home-based care service is to enhance mutual support between the different systems such as patient, family, home-based care, clinic, hospital and NGO services (WHO, 2008). This system allows for referral between all partners as trust and capacities among these partners develop. More importantly, the family and patient are the focus of the care and support and are supported by a large network of services such as home-based carers, clinics, hospital, and the larger community (Mwinituo, 2006; Uys, 2001).

Fourth is the specialised or private home-based care which has been adopted mainly in developed countries that have enough resources to cater for a small number of HIV-infected people. Specialists (i.e. physicians and HIV-specialized nurses) in the area of HIV/AIDS look after the PLWHA at home and have linkages to hospitals. In the case of Namibia, few private agencies are linked to general practitioners and provide services in accordance with treatment plans (MOHSS, 2006). In this model as a whole, patients with complications are referred to

general practitioners and hospitals for admission. However, what needs to be recognised is that these specialised services are not affordable to the majority of the people in developing countries who often do not have medical insurance (Ncama, 2005).

Fifth, the informal home-based care is where families care for their members at home with the informal assistance of their social networks. In this model, usually care givers do not get any form of formal training or external support (Ncama, 2005). This model of HBC is the least effective. However, most HIV/AIDS care in Africa occurs in this model (Uys, 2003).

2.5 Social and Economic Issues of HBC

The objective in this section is to explore some social and economic issues that impact on the HBC system. The social issues of the HBC system are centred on the social impact of the HBC system. In particular, social impact can be described as the achievement of consistent improvements in the lives of people (Non-profit Periscope, 2009). Likewise, central to HBC is the enhancement of the quality of life of people living with HIV/AIDS and their families (Republic of Kenya. 2006). In particular, HBC can provide psychological and spiritual support to those that are affected, including their families (Republic of Kenya, 2006).

The economic issues of HBC relate to the cost of care that can drain the financial resources of the carers and families. More importantly, HBC can be seen as part of the care economy. The care economy relates to unremunerated work undertaken within the house. The unremunerated work ensures the physical, social and psychological maintenance and development of family members. It also includes ‘volunteer` activities in the community that keep the social fabric of society in good order (Elson, 2005). This unpaid work primarily

performed by women is critical to productivity in the paid economy because it sustains the families, allows children to go to school and frees the time of other household members to generate income (Akintola, 2008). This work also provides a crucial contribution to the broader social and economic development of a country (Ogeden, 2006). Gender bias is found in the under-recognition and low value assigned to care economy which is part of the unremunerated work performed by women. More importantly, the global estimated value of unremunerated work performed by women is USD11 trillion (UN, 1995).

According to the United Nations (UN) (1995) the value of the time, energy and resources in the care economy is generally unrecognised and remain largely unaccounted for in most systems of national accounts. The UN (1995) estimates that the value of non-market work is substantial, constituting at least half of gross domestic product and more than half of private consumption.

Budlender (2008) states that increased financial cost relating to caring for the sick ranges from costs incurred to provide immediate care (gloves, medicines, and water) to financial outlays for medicines (prescribed, over the counter, from clinical therapists or traditional healers) and users fees for accessing health care services, transportation costs involved with attending clinics, and rising food costs. This means that households that are already suffering from poverty can be burdened further by financial costs of care giving (Demonchy, 2005).

It is argued that extra responsibilities of AIDS-related care can divert the rural labour from productive agricultural work, thereby creating further household food insecurity (UN, 1995; Budlender, 2007). According to Budlender (2007) households with a sick family member face the opposing pressures to work fewer hours and spend more time caring for the sick, or

to work more hours to earn more money to pay for increased expenditures. The financial cost to older carers is worsened by a loss of financial support from their adult children when they become sick (Budlender, 2007).

2.6 Benefits and Challenges of Home-Based Care

The HBC system has a number of benefits as disclosed by Uys (2003), Van Dyk (2005) and Young (2010). First, it affords the patient and the family time to come to grips with the illness, and the impending death of the patient. Second, good basic care can be successfully provided at home. Third, it is less expensive for the family because problems with transport to the hospitals/clinics, time spent on hospital visits, and other related costs are reduced. Relatives can care for the patient while doing other chores. Fourth, because the pressure on hospitals is reduced by home care, doctors, nurses and other health care professionals can use their time more effectively to care for other critically ill patients in hospital. Fifth, care is more personalized, and the patient is likely to feel less isolated from family and friends. The ambience of home prevents the patient from feeling isolated and rejected. That is to say, sick people are comforted by being in their own homes and communities with friends around them.

Sixth, people prefer to face ill-health and death in familiar surroundings rather than in a clinical or hospital ward. Seventh, HBC is less expensive for the country than institutional options (hospitals, hospices) since periods of stay at those institutions are reduced. Eighth, HBC promotes a holistic approach to care. This means that the physical, social, cultural, psychological, emotional, religious and spiritual needs of a patient can all be fulfilled by the

family and the health team. Finally, home-based caregivers are also in a position to identify the needs of children who are affected by the illness of parents or siblings.

HBC also has some challenges. According to Mohammad and Gikonyo (2005), there are four critical challenges to HBC. They include provision of pain relief, poor nutrition, the scarcity of properly trained care providers, and the burden of care which tends to fall on older women and girls. Indeed, most of the HBC work is often carried out by family members who lack contact with professional health care providers and therefore suffer from lack of professional support (Ogden, et al., 2006). Therefore, with limited support the sick people may be inadequately looked after despite the best efforts of their carers and families. Receiving preparatory information, continued training and support from the health care workers can be an important intervention for coping and provision of quality care (Republic of Kenya, 2006). Apart from lack of professional support, caregivers tend to experience poverty, social isolation, stigma, psychological distress, and lack basic skills (Newman, et al., 2009).

A further challenge associated with HBC is the lack of trained caregivers. Mohammad and Gikonyo (2005) argue that properly trained caregivers tend to be scarce. In the case of Namibia, in order to address this situation, family members and community members are recruited and trained to provide care as volunteers (MOHSS, 2006). However, these volunteer caregivers still experience stigma, social isolation, poverty, distress, psychological and, in most cases, lack adequate education in basic care (MOHSS, 2006).

The implementation of the HBC system remains a challenge in developing countries (Shaibu, 2006). For example, in Uganda family caregivers faced serious work overload and low health status (Kipp et al., 2007). Again, in Namibia the challenges of supporting the implementation

of HBC programme included lack of resources, stigma, discrimination and lack of health professionals (MOHSS, 2006). Furthermore, the initial implementation of the HBC system in Namibia faced challenges as some community members perceived the hospital as the best place where care should be provided (MOHSS, 2006). The shortage of human resources and low volunteer motivation among caregivers was also regarded as a critical operational challenge in the implementation of HBC in Sub-Saharan Africa as a whole (Mohammad and Gikonyo, 2005).

Finally, coordination of various players in the HBC system has been identified as a challenge. For example, the work of Village Development Committee (VDC) and Village Health Committee (VHC) within the HBC and Community-based Health Care (CBHC) is not well understood, poorly coordinated and shows poor collaboration between the key stakeholders (MOHSS, 2007). The assessment of community volunteers disclosed the challenges that affect the operational efficiency and effectiveness of the HBC system which includes the following:

- The majority of Community's Own Resource Persons (CORPS) work without adequate support from either the communities they serve or from the health care system.
- There is much variation in the way that volunteers are rewarded and most volunteers lack the necessary skills.

Overall, while HBC has both challenges and benefits, the benefits appear to outweigh the challenges. Challenges can be overcome through focused interventions such as mobilization of resources and empowerment of those involved in HBC such as family and community caregivers.

2.7 The Experiences of Home-Based Care in Selected Countries

The objective in this section is to provide a comparative analysis of HBC systems in selected contexts. These contexts occur both in Sub-Saharan Africa and in Latin America.

In Botswana, the concept of community home-based care (CHBC) was first introduced in 1992 when it became clear that the public health care sector was unable to cope with the increasing number of patients suffering from HIV-related illnesses (Ngwenya and Kyathi, 2006). In 1994, the Ministry of Health institutionalised the community home-based care programme as one way of alleviating the pressure of increasing numbers of HIV/AIDS related hospitalized patients (Ngwenya and Kyathi, 2006). That is to say, the HBC programme in Botswana was developed as a response to HIV/AIDS epidemic which resulted in too many patients being discharged while they still needed care and support. The CHBC in Botswana is not made only for PLWHA but includes other chronically ill people such as those suffering from cancer, diabetes, hypertension, hemiplegia and paraplegia (Ngwenya and Kyathi, 2006).

The community home-based care (CHBC) in Botswana has increased due to a shift from hospital care to CHBC because of the HIV/AIDS epidemic (Shaibu, 2006). However, the health care system in Botswana, like in other parts of Africa, was not designed to cope with a high occurrence of HIV/AIDS and related illnesses (Butale, 2005). A promising observation is that many districts in Botswana are now beginning to initiate a more structured HBC programme which includes counselling and training and involving communities in the provision of health care (Ndaba-Mbata and Seloilwe, 2005). In spite of such endeavours,

there are still re-admissions to hospital due to numerous complications, suggesting poor quality care at home (Ndaba-Mbata and Seloilwe, 2005).

Some challenges have been identified as they impact on care giving especially by older women and young girls in Botswana. These relate to poverty, isolation, stigma, and lack of knowledge and skills for providing appropriate care (Ncama, 2005). Again, sometimes family members are often not aware of available resources and lack professional and material support (Hughes, 2008). Furthermore, Botswana faces challenges in the implementation of HBC (Browning, 2008). This is due to a number of factors such as the shortage of nurses and social workers, challenges of transportation, poor referral system, financial challenges, fear of stigma and discrimination, overburdening of family members, insufficient support structures for caregivers and poor documentation (Blowning, 2009; Kengethe, 2009).

In Ghana, secrecy and stigma surrounding the HIV/AIDS illnesses poses a major barrier to the provision of home-based care (Radstake, 2005). At the same time, the high demand for patient hospitalisation and the limited number of the beds and staff makes it impossible to hospitalise all patients. Consequently, the clinic's health team made up of a medical doctor, community health worker, a volunteer, and a ward assistant decided it would be more appropriate to care for some patients in their homes (Hughes, 2008).

Ghana's strategy for the provision of HBC includes community education on home-based care nursing, counselling services, and moral and social support to community and family members (Mensah, 1994). The strategy incorporates home-based care into the existing programmes of health care such as tuberculosis care, primary health care services and

mother-and-child health care and education (Baker, 2005). The HBC programme in Ghana is sustained by donations from international and local organisations (Mensah, 1994).

In South Africa, many community home-based care (CHBC) programmes were initiated by concerned individuals, especially retired nurses and church organisations. The integrated community-based home care model was developed in a rural hospice in South Africa in the mid-1990s to deal with the HIV/AIDS pandemic (Ncama, 2005). The aim of this HBC model is to provide a continuum of care especially for PLWHA. The model specifically aims at developing a care system that is effective and sustainable in the context of a developing country (Uys, 2003). However, few volunteer health workers in South Africa have any formal basic education. They work with little or no payment to cover their expenses (Campbell, et al., 2008).

In the case of Tanzania, diseases like HIV/AIDS have imposed a huge burden on the limited hospital beds available (WHO, 2005). Consequently, HBC became the only feasible option and one of the main strategies to provide support to PLWHA in the country (Brady, 2005). Furthermore, there has been a concerted effort by the government of Tanzania since 2003 to scale up the support for home-based care (Duffy, 2005).

The main implementers of HBC in Tanzania have been non-governmental organisations; faith-based organisations and community organisations with support from several donors (Randy and Richard, 2006). At the end of 2007, the National AIDS Control Project (NACP) reported that over 50 000 patients had benefited from HBC (Randy and Richard, 2006).

In Uganda, there were 110 000 children infected with HIV by the end of 2001, necessitating a need to provide home-based care and support for their families (Shater et al., 2006). Eddie, et al. (2005) argue that an estimated 69% of PLWHA in Uganda preferred to be cared for at home because of the constraints of space, facilities and human resources in hospital. For example, Uganda has a doctor/patient ratio of 1:50 000 particularly in rural Uganda, a nurse patient ratio of 1:43 000 and 88% of the population live more than 10 kilometres from any of the health care facilities (Campbell, 2005).

There were 39 registered HBC programmes in Uganda in year 2000, a likely underestimate as many community-based organisations (CBOs) operate as unregistered HBCs (O'Hare, 2005). Some HBC programmes in Uganda are initiated and operated within the community in the form of community-based organisations while others are non-governmental organisations operating from hospital facilities or community clinics, and a few are linked to government facilities (O'Hare, 2005). While Uganda's HBC system has brought several benefits, there are still challenges associated with shortage of drugs and shortage of trained staff (Mohammed and Gikonyo, 2005).

In Zimbabwe, home-based care for HIV/AIDS patients has been developed in response to the rising economic costs of hospital care, the shortage of beds and limited benefits of hospitalising patients who may be cared for at home (Zimbabwe Government, 2011). That is to say, HBC programmes in Zimbabwe emerged as alternatives to institutionalised medical care (MoHCW, 2006). Since 2005, Irish AIDS has supported HBC initiatives in Zimbabwe and is currently funding 15 HBC programmes throughout the country (Irish AIDS Health Development, 2007). The Zimbabwe HBC programmes are linked to hospitals and patients are discharged from hospital and referred to HBC programmes (MoHCW, 2006). The HBC

programmes cater for clients with all chronic illness including HIV/AIDS, diabetes, hypertension, cancer and heart disease.

There are several challenges that affect HBC programmes in Zimbabwe. Indeed, many HBC programmes and services have been affected by socio-political and economic decline and poverty (Irish AIDS Health Development Network and SafAIDS, 2008). Furthermore, reduced donor support has also undermined the effectiveness of HBC programmes (Information Dissemination Service, 2008). Finally, there remains limited access to quality HBC especially in rural areas (Zimbabwe Government, 2009).

In Namibia, the first HBC programme started in 1992 as an HIV/AIDS care programme by the Namibia Red Cross Society (NRCS) (NRCS, 2006). It started with 54 care supervisors, 231 facilitators and 77 peer educators (NRCS, 2006). The programme now covers the whole country.

HBC for chronically or terminally ill patients and their families is primarily available through both trained and untrained care providers. These care providers are supported by various faith-based organisations (FBOs) community-based organisations (CBOs) and the Ministry of Health and Social Services (MOHSS, 2010). In 2006, community-based volunteers reached a total of 39 330 PLWHA, equivalent to 69% of those eligible, providing mostly HIV/AIDS related care (MOHSS, 2006). In 2007, the Namibia Non-Governmental Organisations Forum (NANGOF), the umbrella body for civil society organisations (CSOs), registered more than 290 civil society organis,ations that jointly support more than 20 000 volunteers most of whom providing health care and support (MOHSS, 2010). About 80% of the volunteers were

women and the average age was 27 years against an average 40 years of age amongst their clients. Health centres and outreach points act as the referral centres (MOHSS, 2010).

The HBC system in Namibia is not evenly spread. For example, out of 96 constituencies, 29 are not covered by any formal HBC (Niikondo, 2010). Furthermore, the HBC programmes in Namibia face some challenges such as lack of resources, and lack of communication between families and HBC groups. For example, some primary caregivers felt that home-based carers did not provide them with enough attention and were only interested in the sick person (MOHSS 2007).

In the case of Brazil and, more specifically, in Sao Paolo the Catholic nuns started Project Hope in the late 1980s to provide support and care for families affected by AIDS (Ministry of Health, Brazil, 2004). Project Hope had more than 100 volunteers who each gave a few hours of their time per week (Brazil, 2005). The volunteers each visited a few families where parents were ill. They provided basic home care, counselling and helped care for children. The project also looked after children once their parents had died.

The expansion of HBC in Brazil is associated with the medical plan *viz* the Family Health Programme which was introduced in the 1990s to make use of the large numbers of community health agents (Macinko, 2006). The Family Health Programme was part of the public health system in Brazil consisting of a network for diagnosis, prevention, treatment and follow-up services and included 397 accredited hospitals, 79 day-care hospitals, 58 home-care centres and 422 outpatient facilities (Brazil, 2004). Overall, Brazil has made impressive progress in its Family Health Programmes because of the close ties between the civil society groups and the government (The Economist, 2007).

2.8 Conclusion

The discussion in this chapter has shown that HBC is an important aspect of the health care system. In terms of its development, HBC formally originated in USA in the late 1980s in

response to the rising costs of hospital care. By contrast, in Africa family care has long been part of life despite not being formalised. Families are the central focus of care and form the basis of the HBC system that provide support and care to individuals and families. Within the economy, HBC is considered as unremunerated work. It is part of the work that ensures the physiological, physical and social maintenance and development of family members. In most cases this work performed by family members as primary caregivers is critical to the productive economy or remunerated economy because it sustains families and allows other household members to earn an income. While HBC is an alternative to rising costs of hospital care, it can drain the financial resources of affected families.

CHAPTER 3: DATA ANALYSIS AND FINDINGS

3.1 Introduction

Home-based care is characterised by the provision of a comprehensive health care that is provided across the continuum of care from the health facility through to the community or household level. It encompasses clinical care, nursing care, counselling, psycho-spiritual care and social support (WHO 2006:53). Typically, home-based care (HBC) programmes are geared towards providing a continuum of care to terminally ill patients (UNGASS, 2006). In Namibia, as in many other parts of Sub-Saharan Africa and the world at large, the evolution of home-based care has been in response to terminal diseases like cancer, HIV and AIDS, tuberculosis, just to mention a few as these diseases overwhelmed public health and welfare systems which could not cope with the demands of the epidemic. As such, HBC is characterised by a progressive movement from a vertical palliative home-care programme to one that is integrated and holistic and meets the medical, psycho-social, spiritual and emotional needs of the patients (Ncama, 2005). As a vertical programme HBC is characterized by a continuum of care which links households, community, clinics, and hospitals in a vertical way. By contrast, in a more horizontal form of HBC, there is increased collaboration between the formal (clinics and hospitals) and informal (traditional practitioners) health systems (Aantjie, 2014).

Indeed, Kenya's National Home-Based Care Programme and Service Guidelines emphasise the holistic and collaborative aspect that occurs between the patient and the community in order to enhance the quality of life of the terminally ill patients and their care-givers (Kenya, 2006). This emphasis highlights the way HBC emerged as a variation of hospital care and in response to social and economic issues as well as challenges associated with the care needed

by terminally ill patients whose demands may not be fully met by the formal health delivery system alone (WHO, 2008; Akintola, 2014).

The aim in this chapter is to provide an in-depth analysis of the issues that emerged from the data analysis and, therefore, point to key findings in this study. The rest of the report is organised into seven sections of material. The first section provides the research methods used in this study. The second section provides an in-depth analysis of the evolution of the HBC systems and different kinds of HBCs. Section 3 examines the role of different actors and their interactions within the HBC systems. In Section 4 the attention turns to key social and economic issues of HBC and Health systems including specific benefits and challenges of HBC. A particular attempt is made to locate the HBC within the care economy. The last section explores the implications for social innovation and improved social delivery of HBC. These sections are treated as key themes in this chapter.

3.2 Methods of Data Analysis

The qualitative research methods and, more specifically, qualitative content analysis were used in this study. Qualitative content analysis in published literature highlights conflicting opinions and unsolved issues regarding meaning and use of concepts, procedures and interpretation (Graneheim, and Lundman, 2004). In this study, content analysis was used to identify themes, perspectives and meanings attached to issues discussed in this study. Leedy and Ormrod (2010) also concurred with Neuman (2006) by highlighting that qualitative research design suits studies where the researcher describes the meaning and reveals the nature of certain situation or interpretation that enable the researcher to discover the problems that exist within a phenomenon. The content material from various related forms of literature was analysed through appraising and synthesis of the content using a structured approach and

principles of systematic review (Comerasamy, 2012). Appraising involved an analysis of how the authors have arrived at their findings, themes and conclusions whereas synthesis of the data examined the findings in their context (Comerasamy, 2012). The analysis was guided by research objectives that include:

- To explore the evolution of the HBC system and the different kinds of HBC.
- To examine the roles of different actors and their interactions in order to determine knowledge flows and boundaries of the system.
- To explore the benefits, challenges, and contradictions within the HBC system in order to determine implications for social innovation and improved social delivery of HBC.

As part of innovation studies, the analysis of this research was further guided by the Local Productive and Innovative Systems (LIPS) methodology which provides an analytical framework for understanding the systemic and interactive processes that lead to social innovation. Social innovation derives from an interactive and transforming dynamic, developed with the participation of local actors and appropriated by them, representing solutions to social challenges and to the improvement of living conditions (De Matos, Soares, and Cassiolato, 2012).

According to De Matos, Soares, and Cassiolato (2012) the LIPS methodology pays specific attention to the following dimensions:

- Territorial dimension particularly with the need to contextualize the study within its geographical set-up.
- Diversity of activities undertaken by diverse economic, political and social actors. One of the critical aspects of the study relates to the acknowledgement of the diversity of activities, actors such as families, community volunteers, NGOs as well as hospitals.

More specifically, the diverse actors include families that provide care to the patients, community volunteers who give health educational awareness on how to prevent diseases, hospitals that provide services to the patients and NGOs that provide financial support.

- Tacit knowledge can be observed as non-codified, locally-specific knowledge that develops over time as a result of territorial proximity and/or cultural, social, and commercial identities.
- Interactive innovation and learning are regarded as the central focus of the analysis.
- Governance refers to different ways of coordination among actors influencing the process of decision-making and shaping of social innovations.
- Degree of embededness means the degree of commitment and articulation of HBC actors.

Considering territorial dimension as the key argument, the study was viewed within the national systems of health care in Namibia. The territorial dimension took into account the context in which innovation occurs in Namibia and comprises the physical space as well as the broad economic, social, cultural (symbolic and cognitive), political, urban and rural environment. Special consideration and integration of the above mentioned dimensions of the Local Productive and Innovative Systems (LIPS) lead to social innovation that brings about solutions to some challenges faced in HBC as a continuum of care.

3.3 Evolution of the HBC System and Different Kinds of HBC

It has emerged in this study that HBC evolved as a response to social and economic challenges associated with the care needed by the patients (Roots, 2013). On the one hand, hospital care was increasingly becoming too expensive. On the other hand, the families and other caregivers found it difficult to cope on their own with the demanding nature of caring

for sick people (Spier and Edwards, 1990). At the same time, the evolution of HBC was a response to the social impact of the HIV/AIDS epidemic where the care needed goes beyond medical care because of long-term progression of the disease (MOHSS, 2007; Mwinituo, 2006).

It has been noted that family care as a form of HBC has been part of life in Africa though it was not formalised (Uys, 2003). In Sub-Saharan Africa and other developing countries, HBC programmes were developed as unsystematic and as need-based efforts when it became evident that other options of care were necessary to deal with effects of HIV/AIDS and other terminally illness such as cancer and tuberculosis (WHO, 2006).

As noted by Spier and Edwards (1990) formal HBC programmes started in the USA in North America and Europe in the late 1980s as a result of expensive hospital-based care. Again, in the case of Zimbabwe, HBC developed in response to the rising economic costs of hospital care and the shortage of beds, and in recognition of the limited benefits of hospitalizing many patients (*Rodlack*, 2009). More importantly, the Zimbabwean HBC programmes are linked to hospitals and patients are discharged from hospital and referred to HBC programmes (MoHCW, 2006). These HBC programmes cater for clients with all chronic illnesses including HIV/AIDS, diabetes, hypertension, cancer and heart disease (Zimbabwe, 2011). Similarly, in the case of Namibia the HBC programme started in 1992 as an HIV/AIDS programme by Namibia Red Cross Society (NRCS) consisting of care supervisors, facilitators and peer educators (NRCS, 2006). In Africa, the emergence of HBC is associated with NGOs. Non-governmental organisations (NGOs), community-based organisations (CBOs), faith-based organisations (FBOs) and concerned individuals initiated community home-based as support mechanisms for the hospital system (Nnamndi-Okagbue, 2006; Ncama, 2005).

The other thrust of these organisations was to empower families and communities to respond to the impact of the chronic illnesses such as cancer, HIV/AIDS, diabetes, hypertension and other related diseases by supporting them throughout the process of patient care (Ngwenya and Kyathi, 2006; Young, 2010). Indeed, most of the chronically ill patients need continuous care in their homes from family members and community members (Browning, 2008). As noted by Butale (2005) and Ngwenya and Kyathi (2006) the aim of HBC programmes is to share the responsibility of caring for the terminally ill patients among hospital care, community and family members.

The types of HBC include clinical care which consists of clinical management for chronic illnesses such as cancer and HIV/AIDS. Furthermore, counselling and psycho-spiritual care is a professional assistant relationship that helps people to understand and deal with their challenges (Vhulmani, 2007). Social support creates an enabling environment within the HBC (Sartorie, 2006; UNSAID, 2011).

3.4 The Roles of Different Actors and Their Interactions within the HBC System

The actors within the HBC system include families, community volunteers, and community health workers. Families are the central focus of care and form the basis of the HBC system. Homes are places where people live and provide a source of support and care to individuals and families in need (Committee on a National Strategy for AIDS, 1986; Ncama, 2005). Family members serve as primary caregivers and community members are recruited and trained to provide services as volunteer caregivers (Akintola, 2004). Usually, family members who serve as primary caregivers do not have any form of formal training or external support, but provide basic primary care and informal assistance such as palliative care, counselling, psycho-spiritual care and social support (Ncama, 2005). Overall, the family home can be a

place where the patient gets shelter, love and attention and can express him or herself freely than in hospital. Thus, family involvement and the community participation within available resources and in collaboration with health care workers encompasses clinical care, nursing care, palliative care, counselling and psycho-spiritual care and social support (Ncama, 2005; Sartorie, 2006).

Volunteers are secondary caregivers in the form of community members who may receive basic training that includes supportive counselling services of patients and families, cleaning and dressing wounds, oral hygiene and supervision of medication, necrotic wound care, pain management, and diagnosis of opportunistic infections (Ncama, 2005). Furthermore, community volunteers provide health education about preventable diseases including HIV/AIDS (Kija, 2011). Volunteer caregivers are usually not members of the patient's family.

Nnamndi-Okaghbue, (2006) supported the emergence of HBC by arguing that the role of NGOs and government can be highlighted. NGOs such as Lilonga Eparu in Namibia provide training to family members in providing care for the chronic illnesses (Akintola, 2008). The programme Lilonga Eparu (Learn to Survive) organises awareness campaigns, workshops and basic health educational training on how to take care for terminally ill patients, and how to prevent themselves from getting terminal diseases. In Namibia, these programmes are often organised by NGOs such as Lilonga Eparu in collaboration with Ministry of Health Social Services. Furthermore, home-based care organisations recognise the importance of providing home-based carers with adequate training such as supportive counselling services, cleaning and dressing wounds, oral hygiene and supervision of medication taking, necrotic wound care, pain management, and diagnosis of opportunistic infections (Ncame, 2005).

The inclusion of patients in HBC training can enable their active involvement especially in decision making, planning and implementation of HBC programmes (Maluwa et al., 2007). With the advent of the antiretroviral drugs, many bed-ridden patients have recovered to become active caregivers themselves (Akintola, 2008). Their personal experience as HBC patients living with the aspirations, expectations and needs of a HBC client cannot be substituted for any other experience or knowledge (Maluwa et al. 2007). Getting them on board to make decisions, plan and implement HBC programmes brings in a unique combination of conceptualisation and anticipation of HBC clients' needs that cannot be obtained elsewhere.

3.5 Social and Economic Issues of HBC and Health Systems

Despite the social and psychological comfort that patients receive through HBC, social challenges such as stigma and discrimination exist among patients receiving home-based care (Mwinituo, 2006). Stigma and discrimination result in negative attitudes of neighbours, relatives as well as health care workers towards caregivers and terminally ill patients. Negative attitudes arise as a result of lack of knowledge on issues of terminal diseases and this makes the terminally ill patients to develop fear and suffer, mostly at the hands of their people (Makoae et al., 2009). Once people identify and label your differences, others will assume that is just how things are and the person will remain stigmatised until the stigmatising attribute is undetected (Jacoby, 2005).

The HIV infection carries the stigma of immorality, promiscuity and prostitution in Africa, and stigma associated with the disease and its related shame has increased (Rodlack, 2009).

More particularly, stigma may be described as a label that associates a person to a set of unwanted characteristics that form stereotypes (Jacoby, 2005). With respect to HBC of terminally ill patients, carers sometimes try to keep the status of those in their care a secret for fear of the stigma and discrimination they may suffer, while the volunteers in the HBC programmes are often assumed or suspected to be sick themselves (Budlender, 2007). Furthermore, perceived and actual stigma means that carers fail to access the available formal support from social workers as well as hospitals and informal support from the community for those in their care and for themselves, and miss out on important information and advice on sick people (MOHSS, 2007). However, the attribute that society selects differs according to time and place. What is considered out of place in one society can be the norm in another society. When society categorises individuals into certain groups the labelled person is subjected to status loss and discrimination (Jacoby, 2005).

Another social issue associated with HBC is leadership that includes family members, community volunteers, and social workers that provide counselling as well as social support (Kapoly and Magezi, 2005). HBC leadership has a role of sustained leadership involving articulating, implementing, monitoring, evaluating and being accountable for relevant chronic disease responses in HBC (MOHSS, 2010). Monitoring and evaluation entail follow up of all those offering counselling services to provide technical support and ensure quality (Hansen, et al., 2009). The monitoring and evaluation framework is there to measure progress towards the achievement of HBC goals. As reported in the Medium Term Plan (MTP) III (2006), there is poor articulation and monitoring within the overall leadership for the expanded national chronical diseases response in Namibia (Republic of Namibia, 2006). Ineffective monitoring and evaluation of HBC programmes makes it difficult for the relevant authorities and financiers to come up with sustainable solutions to the challenges faced in HBC.

The cost, both direct cost such as paying for transport and indirect cost such as time lost from work, associated with going to hospital regularly also means that being cared for at home is often inevitable rather than a choice. The financial costs related to caring for the sick range from costs incurred to provide immediate care such as rising food costs, medicine, gloves, water, and transportation costs involved with attending clinics for routine check-ups among others (Budlender, 2007). The other emerging finding is that households with a sick family member face the opposing pressures to work fewer hours to spend more time caring, or to work more hours to earn more money to pay for increased expenditures (Budlender, 2007). This is indeed a social and economic challenge facing the carers. A close analysis of the current HBC system based on the literature reviewed shows that even though the HBC system has economic costs that can be comparable to the hospital-based care, the HBC system is different from hospital care given that HBC allows the terminally ill patient to be in the care and company of his/her loved ones without any time restrictions. The strength of this HBC approach is the dignity and privacy it gives to the patient and his/her family; the patient is cared for in the comfort of the patient`s home (Ncama, 2005). HBC is different because it focuses on the whole person including the non-medical care needs of the patient whereas hospital-based care is focused on the disease and ignores the non-medical care needs of the patient (Beechey, 2004). However, a drawback to this approach is the likelihood of patients wanting to be cared for at home, even with conditions that are beyond the scope of care for the home-based carers (Ncama, 2005).

In spite of the willingness of HBC support systems to provide care to patients, HBC programmes receive limited support from government and also from donor agencies to fund caregivers' salaries (Akintola, 2005). Carers' workloads may be very heavy; they include the

services associated with physical, social and psychological development of family members, changing bandages and toilet assistance. This is referred to as the care economy in economics literature (Akintola, 2008). This leaves care organisations with little option but to rely primarily on volunteers to provide care (UNAIDS, 2006; Akintola, 2008).

On a community and family level, financial costs of care burdens the already poor families and community members especially in the rural communities. Studies in South Africa indicated that some of the isolated areas have limited access to formal clinics and hospitals and community members in most cases are returned home without being given basic health services and suffer from inconsistent quality of care (Mbula et al., 2011).

3.6 The benefits and challenges of the HBC system

Similar to other developing countries in Sub-Saharan Africa, having terminally ill patients cared for at home can be more appealing to governments than treating patients at hospital. For example, one South African hospital reported patients' average stay reduced from fourteen days to three and half days when referred to home-based care (HBC) organisations (Ogden, 2006).

The other benefit of the HBC system includes its availability and affordability. Affordability is supported by the fact that HBC system is less expensive for the family because problems with transport to the hospitals/clinics, time spent on hospital visits, and other related costs are reduced (Uys, 2003; Van Dyk, 2005; Young, 2010). The availability is significant as the family members and community volunteers are available as care givers for the PLWA in an HBC system. The care givers (family members and community volunteers) are also available

to provide the physical, social, cultural, psychological, emotional, religious and spiritual needs of HIV/AIDS patients (Uys, 2003; Van Dyk, 2005; Young, 2010).

Home-based care facilities provide relationship between the families and terminally ill patients where care and support become inclusive and holistic as the patient is cared for both physically, spiritually, emotionally and socially by home-based caregivers. The patient care arrangement has increased the uptake of treatment by the terminally sick patients and their community at a large (National Home-Based Care Programme and Service Guidelines- Republic of Kenya, 2006).

Additionally, HBC provides personalised basic care at low costs and is essential for the fulfilment of the psychological, emotional, religious, social and spiritual needs of a patient and that of the family. The health team includes doctors, nurses, other medical caregivers such as pharmacists, paramedical staffs that are in the part of patient management such as psychotherapists, laboratory, technologists and social workers. (Uys, 2003, Van Dyk, 2005 and Young, 2010, National Home-Based Care Programme and Service Guidelines- Republic of Kenya, 2010).

Although it can be noted that the HBC system has several benefits, there are also challenges associated with the system. Family members might not have capacity to care for the patients as is done at hospitals. According to Hughes (2008) quality should be improved by using quality improvement strategies such as measuring the quality of home health care. This is done by observing structure measures that assess the accessibility, availability as well as quality resources (Hughes, 2008).

On the other hand, as argued by Kipp et al. (2007), family caregivers are facing serious work overloads and low health status and that drains them emotionally (Vhulmani, 2007). This situation puts family caregivers at risk of reduced health status, increased social isolation and depression. Furthermore, care providers lack resources such as adequate medication, food, gloves and other necessities to utilise in the care of their patients (Kapoly, 2005).

Mohammed and Gikonyo`s (2005) findings highlight the issue of human resources such as limited trained caregivers and trained personnel to administer drugs as a key challenge faced by HBC programmes. As such, immediate attention should be given in the areas of training, capacity building and technical expertise (Rodlack, 2009). It also emerged from the findings that volunteers need to be motivated since they are essential to the sustainability of the HBC programmes. According to UNAIDS (2010) most caregivers mentioned their love and empathy for the sick as their primary reason for becoming volunteers. They try to place themselves in the shoes of the sick (Akintola, 2010). Moreover, most home-based carers apply to participate in the programme because in addition to other motivations, they do not have work and have hope of future reward and reciprocity (Akintola, 2010). In addition to the above mentioned challenges, there is a problem in recruitment and retention of HBC personnel, and the availability of guidelines and manuals to direct care providers with professional guidance and direction (MOHSS, 2009). However, the non-governmental organisations which are role players in HBC programme have the responsibility of recruiting personnel (MOHSS, 2009).

The other challenge noted from the findings is that the work of Village Development Committee (VDC) and Village Health Committee (VHC) in HBC and Community-Based Health Care (CBHC) is not well understood and as a result there is poor coordination and

collaboration between key stakeholders such as the family and other sectors working at community level (MOHSS, 2007).

There are critical issues to ponder and put in place for a successful home-based care (Van Dyk, 2005; Magezi, 2005). First of all, an environmental scan to establish the needs, resources and networks within a specific community should be performed. For an HBC programme to be successful it is vital to talk to, listen and collaborate with community leaders and with the sick people as well as the families because they are the people directly affected by the HBC programme (Van Dyk, 2005).

Second, establish a dedicated leadership team to spearhead the HBC system. Magezi (2005) asserted that the HBC programme needs a lot of courage. Thus, would-be caregivers and leaders should be courageous so that they may be a good influence on other parishioners towards the acceptance and assimilation of sick people into the church as actors or stakeholders in HBC.

Third, accessing resources to support the HBC programmes; for example, there are financial implications for starting this programme. Volunteers will need logistical support like transportation and equipment to utilise in their course of duty. Equipment required for proper care will include soap, towels, bedpans, etc. (Van Dyk, 2005).

Lastly - establishing support groups for HBC caregivers where they can reflect on their duty, share their challenges, and receive counselling and guidance. In the surroundings of the support group, caregivers can receive educational talks, mentoring, supervision, socialization and participation in income generating projects (Van Dyk, 2005).

From the above-noted points, it is important to consider resource availability, capacity building and back-up support services for the family, community and volunteer care-givers for the success of the home-based care programme. The resources can be made available and allocated accordingly through formal institutions such as hospitals, clinics and non-governmental organisations. This will help to overcome challenges and increase the success of the programme.

3.7 HBC as Part of Care Economy

According Esquivel (2011) the care economy shifts from work to care. According to Razavi (2007) the care economy emphasises the relationship between the care of children and elderly in the domestic arena, and characteristics and availability of care services. However, care work can be defined as activities and relations involved in meeting the physical, emotional and social requirements of dependent adults and children (Himmelweit, 2007; Bedford, 2010).

Home-based care is considered as unremunerated work. Unpaid care work is quite broadly, synonymous with terms such as non-market or the work of social reproduction (Folbre, 2012; Esquivel, 2011). According to Ogeden (2006), the unremunerated work ensures the physiological, physical and social maintenance and development of family members and volunteers` activities within the community that keep the social fabric in good order. It is vital to consider the economic concept of the care economy in the global context of HBC (Ogeden, 2006). This work is performed by women, as primary caregivers, and is critical to productivity in the remunerated economy because it sustains families, allows children to attend school and frees the time of other household members to earn income. Therefore,

unremunerated work can also provide an important contribution to the country`s economic and social development (Bedford and Kate, 2010).

Unpaid work has some benefits to the economy, for example, it is noted that unremunerated work performed by women is estimated to be $11 trillion globally (Europe survey MMM, 2011; Adam, 2010). While the care economy concept contributes a lot to the wider market place, the unpaid work is still invisible and is not included in the national income accounting systems as well as the Gross Domestic Product (GDP) (Folbre, 2012). If unpaid care work remains invisible, this means that the care workers also remain unpaid (Dwyer, 2013). The unpaid work is not valued by society and is not accounted for in labour force and national income because the care economy activities are regarded as non-market productive activities (or non-market work) carried out in households and communities primarily by women (Ogden, 2004). This is because policy makers and programmers assume that women can utilise their time easily to cater for market work and household production. It is also taken for granted that women will be the ones to respond to crises or illnesses (WHO, 2007; Dwyer, 2013). Overall, this is creating a huge burden to women and girls (Chen, 2005).

According to the United Nations Development Programme (UNDP, 2006), most people visualise unpaid work as work done, primarily by women, to care for the family members such as cooking, cleaning, and shopping, as well as care of children, the sick, and the elderly. The issue of gendered unpaid work is highlighted in the research of Beneria (2010). The categorisation of unpaid work, including growing food for own consumption and collecting water and fuel are categorized as non-productive activities, because the unpaid work is uncounted in labour force and national income (UNDP, 2006). For this reason, it remains statistically hidden (Bedford and Kate, 2010) and can also be conceptualised in terms of who

benefits (Pulerwitz et al., 2004). In production-care services, all workers make important contributions to the care economy, and this tends to vary along with levels of economic development (WHO, 2007). With regards to the HBC system, care which is mostly provided by women manifests itself in the way that women are viewed as non-productive but care givers. This is the gendered nature of the care economy whereby men are regarded as productive citizens responsible for providing food for the family while women do the unpaid household chores and take care of the children and the sick.

3.8 Implications for Social Innovation and Improved Social Delivery of HBC

Innovation refers to a process through which organisations incorporate knowledge in the production of goods or services that are new to them and which are geared to meet social needs (Pessoa de Matos, Soares and Cassiolato, 2012). Within a social system such as the health system, innovation may refer to an interactive and transforming dynamic, developed with the participation of local actors and appropriated by them, representing solutions to social challenges and to the improvement of living conditions (Pessoa de Matos, et al., 2012). Phills Jr., Deiglmeier, and Miller (2008) define social innovation as 'the process of inventing, securing support for, and implementing novel solutions to social needs and problems.' Therefore, HBC is a social innovation meant to secure and provide support to PLWHA and people suffering from other chronic disease such tuberculosis as a novel solution to social needs and the problem of taking care and supporting the infected and the affected. This is supported by Van De Ven et al. (1999) as they state that the emergence of HBC has been a social innovation in taking care of the terminally ill patients, particularly PLWHA.

The concept of the HBC system as social innovation is supported by the institutional theory of innovation associated with the transaction economics which state that societies develop

formal and informal institutions, such as culture and norms, to reduce the importance of transaction costs (Williamson, 2000). The HBC system consists of formal and informal institutions that include the family, the community and formal local health centres that work together to provide care, support and treatment at low transactional costs but with high benefits.

To sum up, HBC is regarded as social innovation because it is an innovative programme that takes the needs and ambitions of the community and terminally ill patients to the government for service delivery as well as community development (Bedford and Kate, 2010). Within the healthcare system, various actors can adopt HBC as a social innovation (Rogers, 2005).

3.9 Conclusion

The evolution of HBC is associated with various factors such as the escalating costs of healthcare, and travelling costs to and from hospital. Therefore, HBC emerged as a social response to challenges that were facing society as well as those that are served by HBC. It has emerged from this study that different actors such as family, volunteers, NGOs, clinics, and hospitals play different roles in the delivery of HBC.

The findings further indicate that as much as there are benefits derived from HBC, there are also challenges facing the HBC system. Some of the challenges which emerged from this study include the costs associated with the provision of HBC at the home level, inadequate medical facilities to complement the efforts of HBC, poor infrastructure and socio-cultural issues that have threatened the sustainability of HBC programmes particularly in Namibia and Sub-Saharan Africa in general. The finding also stress that, caregivers are at the heart of HBC interventions. Appropriate policies and guidelines should be put in place to provide

incentives and psycho-social support to caregivers. The next chapter will present the conclusion and recommendations based on the findings in this chapter.

CHAPTER FOUR: CONCLUSION AND RECOMMENDATIONS

4.1 Introduction

The main purpose of this study was to explore HBC from the perspective of innovation systems and as part of the health care systems in Namibia. The study highlighted the social and economic issues that relate to HBC in the Namibian health care system. The research took the form of a secondary research study based on the available published and unpublished sources such as research reports, dissertations, government policies, books and journals. This chapter concludes the research and gives recommendations to the Government of the Republic of Namibia (GRN), the Ministry of Health and Social Services (MOHSS) in Namibia and various stakeholders responsible for the promotion of health care systems, and more specifically, home-based care (MOHSS, 2010). Overall, this chapter concludes the study and draws conclusions and recommendations based on the findings that emanate from the content analysis that was undertaken in this study.

4.2 Conclusions on Findings

The following conclusions have been drawn from the study and have been explained in line with the research objectives which were:

- To explore the evolution of the HBC system and the different kinds of HBC.
- To examine the roles of different actors and their interactions in order to determine knowledge flows and boundaries of the system.
- To explore the benefits, challenges, and contradictions within the HBC system in order to determine implications for social innovation and improved social delivery of HBC.

From the findings presented and discussed in Chapter 3, it is concluded that formal HBC programmes started earlier in in the 1980s in Europe and North America and late 1990s in Namibia with the purpose of providing medication management, palliative (comforting) care and social support to the victims of terminal diseases like cancer, HIV and AIDS, tuberculosis; sharing the responsibility of caring for terminally ill patients, provision of support mechanism for the hospital system and PLWHA and their families; and empowering communities to respond to the impact of terminal diseases like cancer, HIV and AIDS, tuberculosis.

In terms of the roles of different actors of the HBC system and their interactions, it can be concluded that the main actors consist of families, community volunteers, NGOs and government health institutions. These actors perform different functions such as the provision and management of medication, palliative (comforting) care and social support to terminally ill patients. It can be further concluded that the HBC system has proved to be beneficial by being a good successful personalised basic care for people living with terminal diseases like cancer, HIV and AIDS, tuberculosis at low costs, fulfilling the psychological, emotional, religious and spiritual needs of a patient by the family and the health team.

With regards to the benefits, it can be concluded that the HBC system is readily available (family members and community volunteers are available) and is affordable for the family members and the government. Despite some benefits, it can be concluded that the HBC system has some challenges that include HIV-positive persons straining family's resources, exposure to risks of contracting HIV by caregivers, shortage of trained personnel to

administer drugs, and poor coordination and collaboration between key stakeholders and other sectors working at community.

4.3 Recommendations

Considering the findings and conclusions of this study, the Government of Namibia together with various stakeholders such as families, community volunteers, NGOs and government health institutions responsible for the promotion of health, fighting terminal diseases like cancer, HIV and AIDS, tuberculosis and taking care of people living with terminally diseases are advised to take the following actions for continuity and success of the HBC system in Namibia:

- Incorporate HBC into both formal and informal institutions that can play a critical role in the development of HBC.
- Institutionalize the HBC system and integrate it with other initiatives that occur at national, regional, and local levels.
- Introduce capacity-building programmes through training that includes all individual family and community members involved in HBC.

The recommendations should be considered as part of policy development and be given time frames and be monitored for progress and achievement.

4.3.1 Areas for Further Research

A detailed further research or follow-up studies on home-based care to determine implications for social innovation in Namibia is highly recommended countrywide to identify solutions to challenges associated with the HBC system in Namibia.

4.4 Conclusion

The aim in this study was to explore HBC from the perspective of innovation systems and as part of the health care system in Namibia. The study found that the HBC system is beneficial to terminally ill patients, families and various stakeholders but faces some challenges such as straining family's resources, exposure to risks of contracting HIV by caregivers, shortage of trained personnel to administer drugs and poor coordination and collaboration between key stakeholders and other sectors working in the community. Findings and conclusions in this study have been drawn from the content analysis of the secondary literature. It is concluded that the development of the HBC system will benefit the health care sector of Namibia.

REFERENCES

Aantjie. 2014. Home-based Health Care workers.

Adam, V. 2010. Scoping the Australian Care Economy: A Gender Equity Perspective.

Akintola, O. 2004. *A gendered analysis of the burden of care on family and volunteer caregivers in Uganda and South Africa*. A Published Research by Health Economics and HIV/AIDS Research Division. Durban: University of KwaZulu-Natal.

Akintola, O. 2005. *Gendered home-based care: more trouble for troubled. African journal of AIDS Research*, 5(3), 237-247.

Akintola, O. 2008. *Defying all odds: coping with the challenges of volunteer caregiving for patients with HIV/AIDS in South Africa. Journal of advanced Nursing*, 63(4), 357-365.

Akintola, O. 2010. Perceptions of rewards among volunteer caregivers of people living with AIDS working in faith-based organizations in South Africa; a qualitative study.

Akintola, O. 2014. Infection control in home-based care for people living with HIV/AIDS/TB in South Africa: Volume 9, Issue 4. South Africa.

Baker, S. 2005. Home Care: Addressing the needs of people living with AIDS and their caregivers. *HIV/AIDS update, 34 (1): 201- 211.*

Beechey, J. 2004. Home-based care: A viable alternative for HIV/AIDS treatment. Target Issue 4:76. (On-line). Available: uir.unisa.ac.za/bitstream/handle/10500/1741/12chapter3.pdf. (Accessed on 07/10/2012).

Bedford, K. 2010. 'Harmonizing Global Care Policy? Care and the Commission on the Status of Women,' Gender and Development Program Paper No. 7, Geneva: UNRISD.

Beneria, L. 2010. Globalization, Women`s Work and Care needed: The Urgency of Reconciliation Policy.

Budlender, D. 2008. 'Statistical evidence on Care and Non-care Work Across Six Countries,' Gender and Development Program Paper No. 4, Geneva: UNRISD.

Butale, B. M. 2005. Understanding the experiences and socio-economic challenges of informal caregivers of HIV/AIDS patients in Maun, Botswana. Gaborone, Botswana.

Brandth, R. 2005. Coping with HIV/AIDS: A case analysis of the psychological experiences of poor HIV positive mothers and women caregivers on HAAT. The Centre for Social Science Research, Cape Town, South Africa.

Brazil Ministry of Health, Brazil. 2004. *'AIDS: the Brazilian experience'.* Sao Paulo.

Brazil Ministry of Health. 2005. HBC for people living with HIV and AIDS in Brazil. *2005 July: 95(7):1110-1116.*

Comerasamy, H. 2012. *Literature Based Research Methodology*. Retrieved on 22 September 2013 from http://www.slideshare.net/huguette_comerasamy/literature-based-research-methodology.

Browning, E. 2008. Bringing HIV/AIDS Care: Investigating the value and impact of Community Home-based Care in Botswana. Associated Colleges of the Midwest Society and Culture in Africa. Gaborone, Botswana.

Browning, E. 2009. Bringing HIV/AIDS Care Home: Investigating the value and impact of community Home – Based care in Botswana.Gabarone

Campbell, S. 2005. Care of HIV/AIDS patients in developing countries. *Primary Health Care*. 14(8): 22-25.

Campbell, C., Foulis, C. A., Maimane, S. & Sibiya, Z. 2005. *'I have an evil child at my house': Stigma and HIV/AIDS management in a South Africa community. American Journal of Public Health*, 95. 808-815.

Campbell, L. and MacMillan, A. 2012. 'They Have That Heart': Male involvement in community and home-based care in Namibia. Windhoek: VSO RAISA.

CATHOLIC AIDS ACTION. 2005. *Home-Based-Family-Care in Namibia. A practical manual for trained volunteers.* Windhoek, Namibia.

Committee on National Strategy for AIDS. 1986. Confronting AIDS. Direction for public health, health care and research. Washington, D.C.: National Academy Press.

Chen, M. 2005. Progress of the World`s Women 2005: Women, Work and Poverty.

Crook, J.I. 2005. Impact of support services provided by a community-based AIDS service organization on persons living with HIV/AIDS. Journal Association of Nurses .*AIDS Care*. 6:39-40

De matos, M. P., Couto Soares, M. C., and Cassiolato, J. E., 2012. Conceptual and Methodological Framework for Local Innovative and Productive Systems: Guidelines for case studies based on innovation and social inclusion, RedeSist, Brasil.

De Monchy, M. 2005. The importance of the family to children's resilience and coping in adversity. Children in adversity: ways to reinforce the coping ability and resilience of Children in situations of hardship, Oxford refuge study centre.

Duffy, L. 2005. Suffering, shame and silence: The stigma of HIV/AIDS. Journal of the Association of Nurses in AIDS Care, 16(1).2005. 13-20. (On-line) Available: www.ncbi.nlm.nih.gov/pubmed/15903274.

Dwyer, RE. 2013. The Care Economy? Gender, Economic Restructuring and Job Polarization in the U.S. Labour Market. U.S.

Economist. 2007. *Brazil's AIDS Programme: A conflict of goals.* 10 May 2007. São Paulo: The Economist.

Esquivel, V. 2011. Gender, the changes nature of work and Health

Elson, D. 2005. `Unpaid work, the Millennium Development Goals, and capital accumulation.

Europe Survey MMM (Make Mothers Matter) . 2011. Unpaid work what Matter to Mothers a View from the Grassroots, MMM Belgium.

Folbre, N. 2012. ``The Care Economy in Africa: Subsistence Production and Unpaid Care,`` Paper for the AERC Biannual Research Workshop, 2-6 December.

Graneheim, U. H. and Lundman, B. 2004. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Volume 24, Issue 2 , Pages 105-112, February 2004.* Department of Nursing, Umeå University, Umeå 90187, Sweden. (Accessed on 27/10/2012)

Hansen, K. et al. 2009. The cost of home-based care for HIV/AIDS patients in Zimbabwe. *AIDS Care*, 10(6):64

Himmelweit, S. 2007. The prospects for Caring: economic theory and policy analysis.

Hughes. R. G. (2008). *Supporting family caregivers in providing care.*

Jacoby, A. 2005. 'Epolepsy and Social identity, the Stigma of a Chronic Neurological Disorder'. The Lavcet Neurology. 4(3): 171-178.

Irish Aids Health Development. 2007. Looking Bach, Mapping Forwards: Research Findings in Home-based care in Zimbmbwe. (On-line) Available: www.safaids.net/files/lookin-bck-mpnfwd-HBC-Rsch-Fundngs07.pdf. (Accessed on 27/10/2012)

IRISH AIDS Health Development Network and SafAIDS. 2008. Looking Bach, Mapping Forwards: Research Findings in Home-based care in Zimbmbwe.

Kangethe. S. 2009. *Critical coping challenges facing caregivers of persons living with HIV/AIDS and other. Terminally ill person: The case of Kange Care Program*. Botswana

Kapoly, J. M. 2005. *The Human condition: Christian perspectives through African Eyes.* Inter-Varsity Press: Leicester.

Kija, M. 2011. Home-based Care for people living with HIV/AIDS: Assessment of knowledge, Attitude and Practice among family caregivers at Ukonga ward in Ilala District.

Kipp, W.; Tindyebwa, D.; Karamagi, E. & Rubaale, T. 2007. How much should we expect? Family caregiving of AIDS patients in rural Uganda. *Journal of Transcult nursing.* 18(4): 358-65.

Leedy, P.L. & Armrod, J.E. 2005. *Practical Research*. Planning and Design. 8th ed. Pearson Education International, New Jersey.

Littrell, M., Thurman T., Chatterji, M. and Brown L. 2007. The Tumaini home – Care Program: A case study. Chapel Hill, NC; Measure Evaluation and Care International.

Macinko, J., Guanais, F.C., de Fatima, M. and de Souza, M. (2006). Evaluation of the impact of the Family Health Program on infant mortality in Brazil, 1990-2002. *Journal of Epidemiol Community Health*. *January 2006;60(1):13-19*.

Maluwa, A. 2007. Perception of People Living with HIV and AIDS Regarding Home-based Care in Malawi.

Magezi, V. 2005. 'Life beyond Infection: Home-based pastoral care to people with HIV-positive status within a context of poverty.' Unpublished Dissertation, University of Stellenbosch.

Makoael, L.N. 2009. 'The impact of taking or not taking ARVs on HIV stigma as reported by persons living with HIV infection in five African Countries'. *21(11): 1357-62.*

Mbula, E. K.; Ndabeni, L.; & Maharaih, R. 2011. Rural Health System in South Africa: Local Innovation and Potential for Social Inclusion. South Africa.

Mensah, M. 1994. Home-based Care for people with HIV/AIDS: Agomany, Ghana. Development in practice. 4(1): 58-62. (On-line) Available: www.jstor-org/stable/4029167?seg=2 (Accessed on 23/10/2012).

Mohammand, N. & Gikonyo, J. 2005. Operational challenges Community Home-based Care for people living with HIV/AIDS in multi-country HIV/AIDS programmes (MAP) Sub-Saharan Africa. Africa Region. African Region Working Paper Series No.88.

MINISTRY of Health and Child Welfare. 2010. The Zimbabwe Health Sector Investment Care 2010-2012: Accelerating Progress towards the Millennium Development Goals, MoHCW, Harare, Zimbabwe. (On-line) Available: www.hindawi.com/isrn/immunology/2012/609128. (Accessed on 27/10/2012)

MINISTRY of Health. 2004. Boletirn Epidermiologico AIDS. Brasilia, Brazil: Ministry of Health.

MINISTRY of Health. 2005. HBC for people living with HIV and AIDS in Brazil, 2005 July: 95(7):1110-1116. (On-line). Available: www.ncbi.nlm.nih.gov/pmc/articles/pmc1449327/. (Accessed on 18/09/2012).

MINISTRY of Health and Social Services. 2006. Plan for National Multi-sectoral Monitoring and Evaluation of HIV/AIDS, 2006/07-2008/09. Directive of Special Programmes. Windhoek, Namibia.

MINISTRY of Health and Social Services & Macro International. 2007. Namibia Demographic and Health Services, 2006/07 . Windhoek, Namibia.

MINISTRY of Health and Social Services. 2007. Namibia Global Fund Programme, Annual Report 2006, Windhoek, Namibia.

MINISTRY of Health and Social Services. 2009. Report of the 2008 National HIV Sentinel Survey, Windhoek, Namibia.

MINISTRY of Health and Social Services. 2010. Country Report to UNGASS: Reporting Period 2008-2009. Windhoek, Namibia.

Mwinituo P. 2006. *Stigma associated with Ghanaian Caregivers of AIDS patients*. *Western Journal of Nursing Research*. 28(4), 369-382.

Namibia Red Cross Society (NRCS). 2006. Home and Community-Based care. (On-line) Available: acw.hcbc.biogspot.com/2006110. (Accessed on 9/10/2012).

National Home-Based Care Programme and Service Guidelines- Kenya, 2006.

National Home-Based Care Programme and Service Guidelines- Kenya, 2010.

National Planning Commission. 2001. Namibia 2001 population and Housing Census, Preliminary Results. April 2002.

National Planning Commission. 2006. Namibia 2006 population and Housing Census, Preliminary Results. April 2007.

National Planning Commission. 2011. Namibia 2011 population and Housing Census, Preliminary Results. April 2012.

Ncama, B. 2005. *Models of Community/Home-Based Care for People Living With HIV/AIDS in Southern Africa.* Journal of the Association of Nurses in AIDS Care (JANAC), 16(3), 33-40, May/June.

Neuman, W.L. 2006. *Social Research method*. Qualitative and Quantitative Approaches., Ally and Bacon., Maryland.

Newman, C.; Makoae, N.; Reavely, E.; Kogarity, L. 2009. Alleviating the Burden of Responsibility: *Report on a Study of men as Providers of Community Home-based HIV/AIDS Care and Support in Lesotho*. Lesotho Ministry of Health and Social Walfare in Collaboration with the Capacity Project. January 2009.

Ndaba-Mbata and Rand Seloilwe, E. 2005. Home-based of the terminally ill in Botswana: knowledge and perceptions. International council of Nurses. *International Nursing Review*, 47(4):218-223.

Ngwenya, B.N & Kyathi, D. L. 2006. HIV/AIDS and access to water. A case study of Home-based care in Ngamiland, Botswana.

Niikondo, A. 2010. *Migrants to cities and towns in Namibia: What their interests are?*

Nnamndi-Okagbue, O. 2006. *The critical analysis of home-based care HIV/AIDS patients*. Namibia, Department of Health.

Non-profit periscope. 2009. *what is social impact? (Online).* (Online). Available from http://nonprofitperiscope.wordpress.com/2009/11/16/what-is-social-impact/

O`Hare, B.; Venables, J.; Nalubeg, J.; Nakakeeto, M.; Kibinge, M. & Southall, D. 2005 Home-based care for orphaned children infected with HIV/AIDS in Uganda. *AIDS Care,* 17(4): 443-450.

Ogden, J. 2006. 'Expanding the care continuum: Bringing carers into focus'. *Health policy and planning 21(*5)

opiyo. P. A. 2008. 'HIV/AIDS and home-based health care', International *Journal for Equity in Health* 7:8.

Phills Jr. J. A., Deiglmeier, K. and Miller, D. T. 2008. Rediscovering Social Innovation. *Stanford Social Innovation Review Number 7:* Informing and inspiring leaders of social change. (Online). Available from http://www.ssireview.org/articles/entry/rediscovering_social_innovation/. (Accessed on 08 January 2015).

Rachlis, B. 2013. *A taxonomy for community–based care programs focused on HIV/AIDS prevention, treatment, and care in resource–poor settings.*

Radstake, M. 2005. Secrecy and ambiguity: home care for people living with HIV/AIDS in Ghana. *Book reviews/ Social Science,* 8(2) 763-766.

Randy, S & Richard, S. 2006. *Care giving at the end of life Journey of Palliative Medicine*, 9(5):1174-1187: (On-line) Available: www.tacaids.gotz/thematic-areas/care-and-treatment/home-based-care-hbc.html (Accessed on 27/10/1/2012)

Razavi, S. 2012. 'The Political and Social Economy of Care in a Development Context; Conceptual Issues, Research Questions and Policy Options,' Gender and Development Program Paper No.3, Geneva: UNRISD.

Rogers, E. M. 2005. *Diffusion of innovations* (5th edition). New York, NY: Free Press.

Republic of Kenya. 2002. *Home-based-care for people living with HIV/AIDS: National home-based care Programme and service guidelines.* Nairobi: Ministry of Health National AIDS/STD Control Programme.

Republic of Namibia. 2006. Medium Term Plan III (MTP III). 2006. *Progress Report 2006.* Windhoek, Namibia.

Rodlack, A. 2009. Home-based care for people living with AIDS in Zimbabwe: Voluntary caregivers' motivations and concerns. *African Journal of Research*. 8(4), 423-431.

Root, R. 2013. A qualitative study of community home-based care antiretroviral adherence in Swaziland.

Rotheram-Borus, M.J. Flannery, D. Rice, E. & Lester, P. 2005. *Families living with AIDS*. *AIDS Care*, 17(8), 978-987.

Sartorie, G. 2006. *Twelve (12) steps to living positively with AIDS*. Windhoek: Catholic AIDS Action, Namibia.

Shaibu, S. 2006. Community Home-based Care in a Rural Village: Challenges and Strategies. *Journal of Trans-Cultural Nursing*, 17(1):89-94.

Shater. A. 2006. *HIV prevalence and incidence are no longer falling in Uganda – case for renewed prevention effects: evidence from a rural area population cohort 1989 – 2005 and ANC survey sixteen International AIDS Conference, Toronto*. THLBO 108, 2006. Retrieved on 10 September 2012 from www.avert.org/auls_Uganda.htm.

Spier, A. & Edwards, M. 1990. *Facing AIDS: A strategy manual*. McGregor, South Africa: SYNCOM publishers.

United Nations. 1995. The United Nations Fourth World Conference on women. Beijing, China.

United Nation General Assembly (UNGASS). 2006. Political declaration on HIV/AIDS, Resolution. *A/RES/60/262, UNGASS 2006, Article 20, pp3.*

United Nation General Assembly (UNGASS). 2010. March. 'BRAZIL *UNGASS Country Progress Report'*

UNICEF. (1998). *More than the loss of a parent. Namibia First Study of Orphan Children.* Windhoek: Capital Press.

Uushona, S.I. 2006. Home-based care provided to HIV and AIDS infected patients in Onandjokwe health District, Namibia.

Uys, L. R. 2001. *Evaluation of the integrated community Based Home Care model.* School of Nursing, University of Natal.

Uys, L. 2003. '*Aspects of the care of people with HIV/AIDS in South Africa. Public Health Nursing.* 20(4): 271-280.

Randy, S & Richard, S. 2006. *Care giving at the end of life Journey of Palliative Medicine*, 9(5):1174-1187: (On-line) Available: www.tacaids.gotz/thematic-areas/care-and-treatment/home-based-care-hbc.html (Accessed on 27/10/1/2012)

Williamson, O. E. 2000. The new institutional economics: Taking stock, looking ahead. *Journal of Economic Literature 38: 595-613.*

William, J.B. & Brown, A. 2007. Working with qualitative data. 5th ed. New Delhi: Sage publisher.

World Health Organization. 2005. 'The World Health Report 2005: Working Together for Health'.

World Health Organization. 2006. *'The World Health Report 2006: Working Together for Health'.*

World Health Organization. 2007. Engaging men and boys in changing gender-based inequity in health: Evidence from programme interventions.

World Health Organization (WHO). 2008. *'The World Health Report 2008: Primary health care.* Geneva: World Health Organisation.

World Health Organization. 2010. 'The World Health Report 2010: Working Together for Health'.

Van Dyk, A. 2005. *HIV/AIDS care and counseling.* 3rd edition. Cape Town: Pearsons Education.

Vhulmani, M. 2007. HIV/AIDS, poverty & Pastoral Care & Counselling: A Home-based Care and congregational systems ministerial approach in Africa.1sted.

Young T. B. K. 2010. *Home-based care for reducing morbidity and mortality in people infected with HIV/AIDS.*

Zimbabwe Government. 2009. ZIMBABWE National HIV/AIDS Estimates. 2009. Final Report .Harare, Zimbabwe.

Zimbabwe Government. 2011. ZIMBABWE. 2011. Country report: reporting period 2010-2011, Harare, Zimbabwe.