

INDIGENOUS KNOWLEDGE AND CAREGIVERS' USE OF DATA ELEMENTS  
IN HOME-BASED HEALTHCARE

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**INDIGENOUS KNOWLEDGE AND CAREGIVERS' USE OF DATA ELEMENTS IN  
HOME-BASED HEALTHCARE**

by

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206026307**

**Thesis submitted in fulfilment of the requirements for the degree**

**Master of Technology: Information Technology**

**in the Faculty of Informatics**

at the

**Cape Peninsula University of Technology  
Cape Town, South Africa**

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**Date submitted: 14 December 2012**

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## DECLARATION

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**Signed**

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**Date**

## ABSTRACT

Home-Based Healthcare (HBHC) is an important aspect of South Africa's healthcare system. HBHC is the provision of care services to patients by trained or semi-trained caregivers at home. In South Africa HBHC was introduced in 2001 to address many problems with traditional healthcare such as overcrowding in public health facilities. South Africa has one of the highest HIV/AIDS infection rates in the world, which is often accompanied by opportunistic infections such as tuberculosis. HBHC is envisaged to address these challenges, thus relieving the burden on primary healthcare. HBHC is itself faced with many problems which include poor information or data management, unclear information flows, and insufficient information storage. It is also not clear how caregivers use data elements and there is no coherent indigenous knowledge base for the capturing, implementation and utilisation of data elements in local HBHC providers. This is particularly important to caregivers who rely on frameworks of indigenous knowledge in interpreting and making decisions on how to provide a care service to patients. In reality, caregivers operate in indigenous environments requiring the utilisation of local knowledge.

This study explores the relationships between, and approaches to, data elements in different HBHC providers and communities. Three interpretive case studies in the Eastern and Western Cape Provinces of South Africa were conducted. Semi-structured interviews, focus groups, participant observation and document analysis were used for data collection. The primary research question was: What happens when caregivers from various communities interact with data elements when providing a care service? Caregivers' indigenous knowledge and use of data elements was then harnessed in a knowledge base. The results from this study can be used by HBHC managers to develop their forms and training materials as the initial set of data elements used in HBHC has been identified. Caregivers from different communities can also learn how these data elements are used in other communities.

The findings show that most HBHC facilities have no control over the forms used during the care process; these are influenced or determined by external sponsors and the Department of Health. Some HBHC facilities do not have the skills or resources to design their own forms and choose which data elements to be included. There are similarities and differences in the way data elements are used in both provinces. Additionally, socio technical factors affect the way caregivers perceive data elements. Even though caregivers are trained before they commence nursing work, the training is often regarded to be inadequate. Often caregivers have to rely on local communities of practice for assistance and guidance with professional activities, understanding the data elements and filling in the forms. Caregivers are required to learn from the community, health care workers and other caregivers in order to improve the quality of care. Indigenous knowledge also plays a vital role during the care process.

This study provides a description of how caregivers use data elements in Home-Based Healthcare and adds to the limited research in South African HBHC. An initial set for core data elements for HBHC has been identified. The collected IK has been captured and stored in a repository and patterns of use and meanings of data elements have been identified. The study will also be useful for HBHC service providers and people who develop the services so that they can provide caregiver training accordingly. Government can use it to understand the difference between care records and patient record.

**Keywords:** Caregiver, data elements, Home-based Healthcare, Indigenous Knowledge (IK), Socio-technical perspective, community learning, Communities of Practice (CoP).

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## DEDICATION

This work is dedicated to Mom, my grandmother, Lukhona, and Phiwokuhle with all my love. Mom, gran, my lovely son and niece supported and encouraged me wholly during the time I pursued my studies. May God bless you and I love you all.

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## **GLOSSARY**

<b>Terms/Acronyms</b>	<b>Definition/Explanation</b>
HBHC	Home-Based Healthcare
IK	Indigenous Knowledge
IKS	Indigenous Knowledge Systems
ICT	Information and Communication Technology
IT	Information Technology
WHO	World Health Organisation
NRF	National Research Foundation
IKS	Indigenous Knowledge Systems
CoP	Community of Practice
DoH	Department of Health
DST	Department of Social Development
DoE	Department of Education
HIS	Hospital Information System
DHIS	District Health Information System
HIV	Human Immunodeficiency Virus
AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
CBO	Community Based Organisation
DSD	Department of Social Development
TB	Tuberculosis
DOT	Directly Observed Treatment
EC	Eastern Cape
WC	Western Cape
EPWP	Expanded Public Works Programme
FBO	Faith Based Organisation
VCT	Voluntary Counselling and Testing

OVC	Orphans and Vulnerable Children
EHR	Electronic Health Record
WHO	World Health Organization
ISO	International Organization for Standardization
IEC	International Electrotechnical Commission
SAFIPA	South Africa-Knowledge Partnership on ICT
CPUT	Cape Peninsula University of Technology
UP	University of Pretoria
NMMU	Nelson Mandela Metropolitan University
USSD	Unstructured Supplementary Service Data
Indigenous Knowledge	Local knowledge that is unique to a given cultural group or society.
Data Elements	A piece of information that separately adds meaning in the patient record
Home-based healthcare	The provision of basic health services by caregivers (formal and informal) to people in their homes.
Caregiver	Can be formally trained nurses to semi-trained or informal carers such as family, friends, neighbours and members of the community
Interaction moment	Is the moment where the caregiver interacts with the data elements?
Electronic Health Record	Repository of patient data in digital form, stored and exchanged securely, and accessible by multiple authorised users
	Repository of information about a single patient, generated by health care professionals as the direct result of interaction with the patient or his relatives

## **PRESENTATIONS STEMMING FROM THIS RESEARCH**

Tswane, S., 2012. Caregivers' indigenous knowledge Presentation at INDEHELA HEI-ICI workshop. October 2011. Eduardo Mondlane University, Maputo, Mozambique.

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Tswane, S., 2012. Approaching a community. Presentation at the 2<sup>nd</sup> ISD4D Seminar and Workshop. 26 -31 March 2012. Eduardo Mondlane University, Maputo, Mozambique.

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## **CHAPTER ONE**

### **1. Introduction and background**

Providing access to affordable and quality healthcare is an important responsibility of any country to its citizens. This responsibility is even more vital in a country such as South Africa with poor delivery of quality healthcare against a background of increasing health burdens due to HIV/AIDS, poverty/socio-economic deprivation, rural-to-urban migration, illiteracy, and diseases of the elderly (Van Zyl, 2011; DoH, 2009). Consequently, the provision of an acceptable level of quality healthcare has not been attained. South African healthcare consists of a large public sector and a small but growing private sector. The public health sector is supported by the state and it provides healthcare services to South Africans free or at a very affordable price. The public health sector includes clinics, district/provincially -aided hospitals, maternity hospitals, midwife obstetric units, psychiatric hospitals, rehabilitation centres, reproductive health facilities, secondary hospitals, specialised health facilities, tuberculosis (TB) hospitals, tertiary hospitals and primary healthcare (Western Cape Department of Health, 2009).

In 2001 South Africa introduced home-based healthcare (HBHC) within the country's healthcare system to provide healthcare services to patients in their homes (National Department of Health, 2001; Cameron, Coetzee, & Ngidi, 2009). This was done to address many problems that public health facilities such as hospitals and clinics experience. These problems include shortage of beds, insufficient healthcare professionals, lack of resources, overcrowding and staff shortages and high costs of institutionalised care (National Department of Health, 2001). Home-based healthcare (HBHC) can be defined as the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death (National Department of Health, 2001; Van Zyl, 2011). HBHC services can be classified into preventive, promotive, therapeutic, rehabilitative, long-term maintenance and palliative care categories (ibid.).

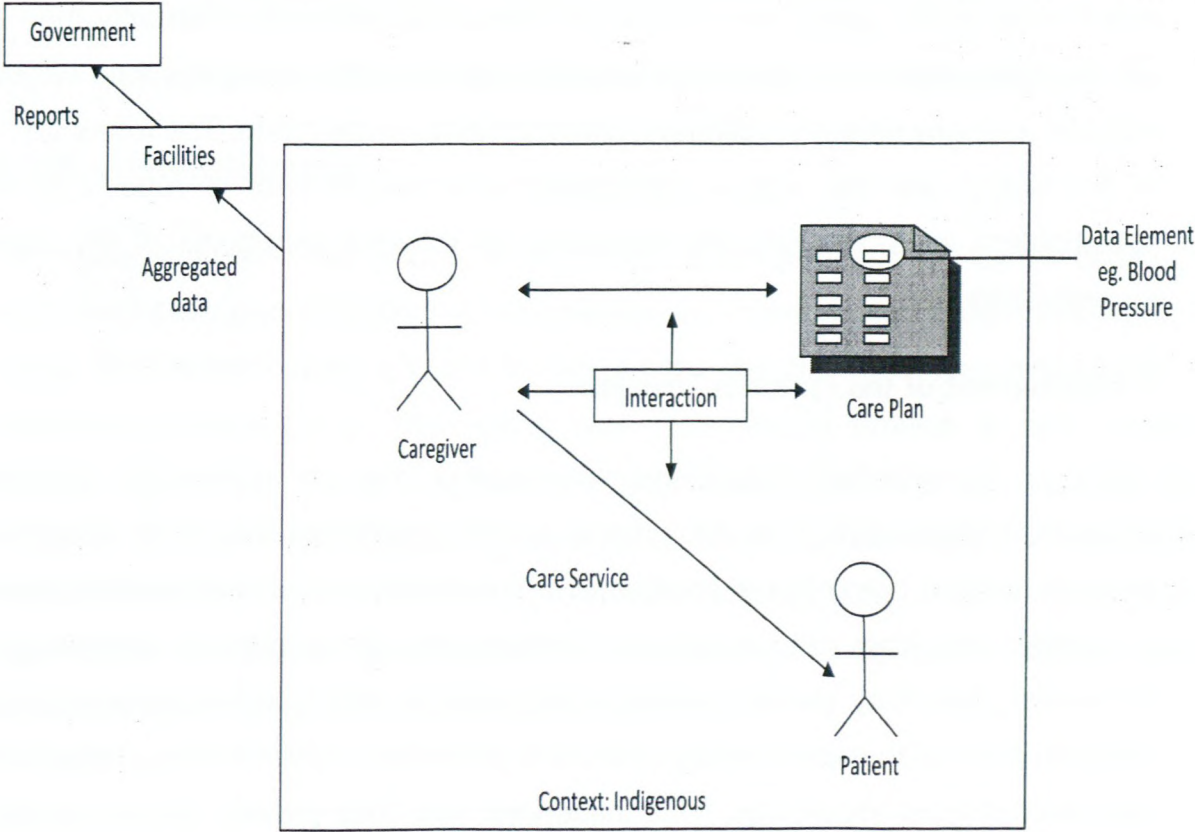
Caregivers can be formally trained nurses to semi-trained or informal carers, such as volunteers and family members. They usually work in the communities where they live. The primary role of the caregiver is to provide basic nursing and palliative care to persons (also referred to as “clients”) in need. This includes post-operation and hospital care as well as long-term care for those suffering from chronic illnesses. Caregivers also identify the needs of the patient and his family, provide support, basic medication, supplies and nutritional supplements where needed. Furthermore, they assist in the referral to other levels of professional services if required.

A Home-Based Healthcare Research Project known as Socio-Tech: Made in South Africa project now known as Kujali was initiated at the Cape Peninsula University of Technology (CPUT) in 2009, and identified some of the many challenges that HBHC in South Africa is faced with. The purpose of this project was to explore the challenges and needs in HBHC, and lay the platform for a solution to the myriad HBHC problems by developing mobile applications to facilitate better healthcare service provision. This was based on the need for care givers to capture, report and share care patient data more easily in order to reduce the time spent on the filling in of forms. Currently all the care patient data that the caregiver is responsible for is still paper-based and even at the facilities there are limited technology available to process data. Initial observations in this project have shown that there are no set standards for data capturing, reporting, and the (universal) utilisation of data elements.

HBHC centres each follow their own standards and this leads to different data elements being used in different HBHC centres. Moreover, the knowledge that caregivers have about data elements and their usage lives in “their heads” and is not stored on paper or any electronic medium. The data elements found in forms (such as blood pressure, temperature, pulse to mention a few) and reports are not explanatory as to why and how they are used, and where they come from. This is a problem as new caregivers do not understand the reasons behind using these data elements, and realise only with experience that they impact on the quality of service given to patients.

In fact, as we shall come to understand, much of the HBHC service in South Africa depends on the aforementioned experience. For the purposes of this examination, I shall refer to this phenomenon as indicative of “indigenous” knowledge. Indigenous knowledge is local knowledge that is unique to any given society or cultural grouping (Aluma, 2004). It consists of actual skills, practices, and/or techniques of doing things developed through practical experience over time by people of the place and adapted to the local situation (Aluma, 2004; Sukula, 2006). It is the basis of how caregivers interpret the care service in a particular context based on their previous experiences and making sense of the care service in their situation. In HBHC it is usually passed down from one caregiver to another.

Initial observations in the project have indicated that the indigenous knowledge(s) of caregivers is not captured adequately (Van Zyl, 2011). This specifically pertains to caregivers’ use of data elements in patient care administration, for example blood pressure, temperature, weight etc. Figure 1.1 below shows the various interaction moments between the caregiver and data elements during the provision of care services.



**Figure 1.1: Caregiver interaction moments with data elements**

There are several forms used in HBHC, these forms vary from care forms used by caregivers when they provide a care service to the patients at home to those used by managers to report to different funders. During care process caregivers get information about their patients on the forms and they have to write the details of the service they provided on different forms. On the forms there are data elements which give meaning to the data on the forms. For example the caregiver can fill in the time spent at the home or observations. These are all data elements. Often people other than the caregivers do not know how these data elements are used.

The study focuses on the interaction of caregivers with the data elements when they provide a care service, put differently how do caregivers understand and use data elements on the forms when they are caring for the patients at home. You might ask yourself "How does one interact with data or data elements?" This is not just the capturing of the data, it goes beyond. The caregivers mostly act as a result of a data element. For example if there is a data element, observation, the caregiver needs to check if the place where the patient lives is in a good shape, the skin appearance, listen to the tone of voice of the patient and many other activities. If the caregiver does not understand what the data element means then they may not do a proper check. Also if the caregivers understand these data elements differently then they will do things based on that. After everything is done the caregiver then writes all they did and saw under the different data elements on the forms. The forms are sent to the facility and the data is aggregated and sent in form of reports to other stakeholders such as DoH and managers or relevant individuals of the funding organisations.

### **1.1. Statement of the research problem**

There is no standard, integrative approach - that is, universally accessible indigenous knowledge base - for the capturing, implementation, and utilisation of data elements in home-based healthcare in South Africa. This is particularly relevant to caregivers, who rely mostly on frameworks of indigenous knowledge in interpreting how they should provide a care service. Indeed, caregivers in Dutywa, Flagstaff and Stellenbosch mostly operate in indigenous environments, requiring the utilisation of local knowledge. This influences how they provide a care service to patients and how they understand data elements.

## 1.2. Research question

The main question that this study considers is: **What happens when caregivers from various communities interact with data elements when providing a care service?** *Additionally, what is the role of indigenous knowledge in caregiver activity, and how does one move toward an approach for capturing and sharing this knowledge in terms of data elements?*

The sub questions are:

- Which data elements are relevant to HBHC, and to caregivers in particular?
- How are data elements presented on different forms and reports in HBHC?
- What is the significance of indigenous knowledge regarding the use of data elements?
- How may indigenous knowledge be better utilised (e.g. captured) in terms of more effective data element usage?
- How are data elements used differently in different communities?
- How are data elements used differently/similarly in different communities?
- Which differences occur in terms of indigenous knowledge uses?

These questions, sub-questions and objectives are shown in Table 1 below.

## 1.3. Research objectives

This study addresses the problem of the lack of a coherent IK base for the capturing, implementation, and utilisation of data elements in home-based healthcare in South Africa. This is particularly relevant to caregivers, who rely mostly on frameworks of indigenous knowledge in interpreting how they should provide a care service. Indeed, caregivers mostly operate in indigenous environments, requiring the utilisation of local knowledge. This necessarily influences how they provide a care service to the patients and how they understand data elements. The aim of the study is to explore the relationships between and approaches to the use of data elements by caregivers in HBHC. The objectives are to:

- Describe the use and presentation of data elements in different HBHC providers
- Identify or define an initial set of data elements for HBHC
- Identify or define a core set of data elements for HBHC from the care forms;
- Describe the differences in the use of data elements in differing HBHC contexts; and
- Harness caregivers' indigenous knowledge of their interactions with data elements
- Identify or define a core set of data elements for HBHC based on the care service provision in different communities.

#### **1.4. Research Design**

The study is qualitative and uses interpretive case studies from three communities in both the Eastern and Western Cape Provinces, respectively the MIDA Health and Poverty Project in Dutywa, Ixabiso Lomntu Community Health Project (both in the Eastern Cape), and Stellenbosch Hospice in Stellenbosch, Western Cape. Primary data was collected through qualitative methods, including in-depth interviews, focus groups, and participant observation. Secondary documents, such as patient forms, were also used. The data was analysed and interpreted using hermeneutics.

**Table 1.1: Research Questions, methods and objectives**

<b>Research Problem:</b>	It is not clear what happens during the capturing, implementation, and utilisation of data elements by caregivers in Home-based Healthcare in South Africa. The role of indigenous knowledge regarding data element usage and capturing is also unclear.	
<b>Research Question</b>	What happens when caregivers from various communities interact with data elements when providing a care service?	
<b>Sub questions</b>	<b>Research method(s)</b>	<b>Objectives</b>
1. Which data elements are relevant to HBHC, and to caregivers in particular?	Literature review , initial observations in CPUT project, interviews, focus groups and participant observation	Describe the use and presentation of data elements in three HBHC providers Identify or define an initial set of data elements for HBHC
2. How are data elements presented on different forms and reports in HBHC?	Initial observations, document analysis, interviews, focus groups and participant observation	Describe the use and presentation of data elements in three HBHC providers Identify or define a core set of data elements for HBHC from the care forms
3. What is the significance of indigenous knowledge regarding the use of data elements?	Observations, focus groups	Explore the role of indigenous knowledge in the daily care service process
4. How may indigenous knowledge be better utilised (e.g. captured) in terms of more effective data element usage?	Interviews, focus groups and participant observation	Harness caregivers' indigenous knowledge of their interactions with data elements Analyse the captured indigenous knowledge to identify patterns of use
5. How are data elements used differently in different communities?	Initial observations, Interviews, focus groups and participant observation	Describe the differences in the use of data elements in differing HBHC contexts Identify or define a core set of data elements for HBHC based on the care service provision in different communities.
6. Which differences occur in terms of indigenous knowledge uses?	Initial observations, Interviews, focus groups and participant observation	Describe the differences in the use of data elements in differing HBHC contexts Identify or define a core set of data elements for HBHC based on the care service provision in different communities.

The study is part of the Socio-Tech: Made in South Africa project at the Information Technology department, Cape Peninsula University of Technology. The project is funded by SAFIPA (South Africa – Finland knowledge partnership on ICT) and is looking at ways to improve the Home-based Healthcare sector in South Africa using information and communication technologies. The repository which will be used for archival of the indigenous knowledge has been developed by one of the students who are involved in the project. The researcher also acted as the caregiver representative and a tester for many ICT projects within the Socio-Tech project.

## **1.5. Conclusion**

The chapter introduced the study, what the research purpose is and what the research outputs are. Background to the research problem, the research question, objectives and methods that will be used to achieve each objective have been included. Chapter 2 will focus on the literature review and what other researchers have done in the research area. The conceptual framework and the theoretical lenses (that is Socio-technical theory, CoP, social representations and community learning) used in the study is also included in this chapter. Chapter 3 will look at the research methodology for the study and ethical considerations. Chapter 4 and 5 will focus on the findings and the discussion of findings. Lastly Chapter 6 will be the conclusion and recommendation including suggestions for future research.

## **CHAPTER TWO**

### **2. Literature Review**

The chapter contains the literature review. The literature was reviewed to identify the issues relevant to this study. The different concepts derived from the literature are presented at the end of this chapter to present the conceptual framework used for this study.

#### **2.1. Introduction**

Several questions were asked based on the literature to establish the current status of research of this topic. Some of these questions are: What is healthcare? What are the different healthcare systems? How are the countries categorised? What are the challenges in African healthcare? What is the form of healthcare system used in South Africa? What is home based healthcare? What role does HBHC play in healthcare? Who provides HBHC service? What role do people play in HBHC? Who receives care? What are the needs of care recipients? How is data recorded? In what form is it recorded? What is the purpose of data recording? What is indigenous knowledge? How is it used in HBHC? What are its benefits? What are its characteristics?

To answer these questions relevant scholarly papers were searched from databases such as Pubmed, Emerald, Gale/Infotrac, Science Direct, Elsevier, Sage, and reputable websites such The World Health Organisation (WHO), The World Bank, United Nations (UN), International Council of Science (ICSU), World Intellectual Property Organisation (WIPO), United Nations Educational, Scientific, and Cultural Organization (UNESCO), UN, International Federation of Library Association and Institutions (IFLA) and Google Scholar.

Phrases such as "South African Healthcare" "South Africa + Healthcare system", "Indigenous knowledge", "Home-based healthcare", "Home care", "Communities of Practice", "Community Learning", "Caregivers + home-based healthcare", "Volunteers + home-based healthcare", "Lay workers + home-based healthcare" were used to search the databases and websites. The results of the search helped with the references used in the study.

## 2.2. Healthcare

Healthcare is a global concern for high, middle and low income (also referred to as developed, developing and least developed) countries. The World Health Organisation (WHO) and the World Bank classify the countries according to their Gross National Income (GNI) per capita previously known as the Gross Domestic Product (GDP) (World Bank, 2002). "Based on its GNI per capita, every country is classified as low income, middle income (subdivided into lower middle and upper middle), or high income" (World Bank, 2002). Incomes below \$935 fall under low income economies. \$936 to \$3,705 falls under lower middle income economies. \$3706 to \$11,455 of per capita income is classified as upper middle income economies and above \$11,455 of per capita GNI qualifies as a high income economy (World Bank, 2002).

The countries such as Finland, United Kingdom, United States of America (US), Canada and Tokyo, with high GNI per capita are referred to as developed or high income countries. While countries such as South Africa, Brazil and India with middle GNI per capita are known as middle-income countries or developing countries and countries with low income such as Zimbabwe, Uganda, Mozambique, Samoa are known as low-income countries or least developed countries. All these countries have different healthcare systems. In developed countries healthcare is largely funded by government through taxes and there is not much difference between public and healthcare sectors.

The healthcare system in Finland is divided into two healthcare systems: - municipal healthcare system and private healthcare system (Teperi et. al, 2009; Järvelin, 2002). Teperi et al. (2009) state that these two healthcare systems work in parallel, complementing each other and sometimes overlap. The private healthcare system uses about 6% of the total healthcare expenditure (Teperi et. al, 2009). The municipal health system is similar to what is known as public healthcare system in countries such as South Africa. It organises and delivers preventative public and primary care services to residents. Municipalities have district hospitals and health care centres (Järvelin, 2002). Health centres can also be jointly owned with several municipalities. Employed residents can use both healthcare systems while unemployed residents only use municipality healthcare (Teperi et.al, 2009). In

Canada healthcare is financed by government through taxes but run privately. It is known as "Medicare" and it is available to everybody (Irvin, Ferguson & Cackett; 2002). This was implemented to eliminate many problems that the public healthcare sector was facing.

Countries such as India and Brazil which are also middle income countries have similar healthcare systems with South Africa. In Brazil, like South Africa and India the healthcare system is divided into two that is private and public healthcare sectors (Alves & Timmins, 2001; Boston Analytics, 2009). Those with adequate funds, or whose employers fund their health insurances, have access to a private system of healthcare that provides quality treatment on demand (Alves & Timmins, 2001). The rest of the population relies on the public health sector. As is the case with most public healthcare systems around the world, the Brazilian system is "characterized by long waiting times and questionable quality, with the practical implication that those who are forced to rely on the system spend more time being sick and, subsequently, have a diminished health stock" (Alves and Timmins, 2001). India still has a serious scarcity of sub-centres, primary health centres, and community health centres and low density of healthcare workers (Boston Analytics, 2009). "The poor state of healthcare in India is caused by the lack of government funding on healthcare initiatives, as estimates reveal that the per capita spending on healthcare by the Indian Government is far below international recommendations" (Boston Analytics, 2009:2).

There are many health risks that lead to death in the world and they have an effect on countries of all income groups; high, middle and low. According to the WHO (2009), primary international risks for death in the world are "high blood pressure (responsible for 13% of deaths globally), tobacco use (9%), high blood glucose (6%), physical inactivity (6%), and overweight and obesity (5%)". WHO (2009) further states that these risks further inflate that of chronic diseases such as heart disease, diabetes and cancer. "Other global risks for burden of disease (measured in disability-adjusted life years - DALYs) include malnutrition (6% of global DALYs), unsafe sex (5%), alcohol usage (5%) and unsafe water and poor sanitation and hygiene (4%)" (WHO, 2009). Three of these risks mostly affect people in low-income

countries, particularly the South-East Asia and sub-Saharan Africa regions (WHO, 2009).

### **2.2.1. African Healthcare**

Africa is made up of middle and low income countries. The continent is faced with many challenges which include lowest human development and high poverty rate worldwide (Ambali, Mugabe & Mutero, 2009). Many African countries have the highest illiteracy rates and the lowest primary education enrolment. All these challenges have an impact on the continents' healthcare. In sub-Saharan Africa, the quick spread of HIV/AIDS has proven catastrophic, and has lowered the life expectancy radically to 46.1 years, compared to the North African average of 71.5 (Ambali, Mugabe & Mutero, 2009). According to UNAIDS (2006), an estimated 63% of all persons infected with HIV lived in sub-Saharan Africa (24.7 million people). An estimated 2.1 million AIDS deaths were recorded in Africa, representing 72% of global AIDS deaths. Southern Africa has the highest prevalence of HIV and AIDS, in 2006, the region had 32% of the people living with HIV globally, and 34% of global AIDS deaths (UNAIDS, 2006).

#### **2.2.1.1. The South African healthcare system**

South African Healthcare system is composed of a large public health sector and a small but rapidly growing private health sector (South African Info, 2010). Healthcare varies from the most basic primary healthcare, offered free by the state, to highly specialised hi-tech health services available in the private sector for those who can afford it (Media Club South Africa, 2009). "The public sector is under-resourced and over-used, while the rapidly increasing private sector, run largely on commercial lines, caters to middle- and high-income earners who tend to be members of medical schemes (18% of the population), and to foreigners looking for top-quality surgical procedures at relatively affordable prices" (South African Info, 2009). The public healthcare sector is faced by many challenges which include lack of facilities which leads to overcrowding, healthcare personnel shortages (Cullinan, 2006).

The public health sector includes clinics, district- and provincially-aided hospitals, maternity hospitals, midwife obstetrics units, psychiatric hospitals, rehabilitation centres, reproductive health facilities, secondary hospitals, specialised health, care facilities, tuberculosis (TB) hospitals, tertiary hospitals and primary healthcare (Western Cape Department of health, 2009). Mobile clinics, clinics and community health centres form primary healthcare which is the lowest level of public health and is freely available to previously disadvantaged individuals, women and children (National Department of Health, 2000). Primary healthcare acts as an entry point or first point of contact into the health system (Health Systems Trust, 2008).

About two-thirds of the South African population relies on the public health. South Africa has high levels of HIV/Aids, TB and other poverty related illnesses (Harrison, 2009). These patients cause overcrowding in hospitals and make it difficult for patients who have other illnesses to access the care. As a solution to this problem another level known as HBHC has been developed and plays a vital role in taking care of these patients who require long-term care in their own homes.

#### **2.2.1.1.1. Home-based Healthcare (HBHC)**

Home-based healthcare (HBHC) can be defined as the provision of basic health services by caregivers (formal and informal) to people in their homes (Van Zyl, 2011). WHO (2000) defines HBHC as any form of care given to sick people within their homes which includes physical, psychosocial, palliative and spiritual interventions. HBHC is considered an alternative to the customary institutionalised care and focuses on palliative care within the home (National Department of Health, 2002). It also provides back-up for people who need extended care, not necessarily hospital care or people who have been discharged early from hospital (National Department of Health, 2001).

The AIDS pandemic and the rise in non-communicable diseases, the ramifications there from and the rise in number of people who are aging had an impact on communities, and South Africa as a whole (National Department of Health, 2001). According to the national DoH (2001) this put a strain on the already limited resources. It became essential to think of better ways to provide care for all the countries population (healthy people, people with disease and their families). As more people became ill, many were unable to stay in hospitals, hospices or other institutions for care (National Department of Health, 2001). In order to provide suitable care and support to patients suffering from terminal illnesses such HIV/Aids, diabetes and hypertension particularly in developing countries such as South Africa an approach that caters for medical, psychological, spiritual and emotional needs became necessary (National Department of Health, 2002).

HBHC addresses many problems that the public health facilities such as hospitals and clinics experience. These problems include shortage of beds, insufficient health, nursing and medical professionals in public health sector, lack of resources for treatment and drugs, overcrowding which makes the facilities unsuitable for terminal or long-term diseases and high costs of institutionalised care (Department of Health, 2001; National Department of Health, 2002). HBHC also caters for people with mental, physical and emotional needs to promote, restore, and maintain an individuals' maximum level of comfort, function and health including towards dignified death. These services are grouped into preventative, promotive, therapeutic, long-term maintenance and palliative care, and are specifically provided by caregivers optometry (Western Cape Department of Health, 2009).

In South Africa, the HBHC service is facilitated mostly by Non-Profit Organisations (NPOs), Non-Governmental Organisations (NGOs), Faith-Based Organisations (FBOs) and Community-Based Organisations (CBOs) (National Department of Health, 2001). However these facilities work together with other institutions. HBHC is an essential part of community-based care. Community-based care is defined as "the care that the consumer can access nearest to home, which encourages participation by people, responds to the needs of people, encourages traditional community life and creates responsibilities" (National Department of Health, 2001:1).

HBHC requires the resources, skills, time, energy and funds of communities and governments and it is understood that healthcare is the outcome of the overall social and economic development of the community (National Department of Health, 2001). Therefore, there is no single unit that can able to meet all the requirements and challenges of HBHC but success is achieved through a collaborative effort. The National Department of Health (2001) refer to "care in the community must become care by the community".

Department of Health (2001) identified five models of care in HBHC. These models include all the levels of society (such as the Department of Health, relevant NGOs/community-based organisations (CBOs), faith-based organisations (FBOs) and the community) that share the goal of and providing sufficient care to patients and their families within the community environment, considering the socioeconomic conditions, needs and limitations (National Department of Health, 2002). HBHC is important in providing complete and continual care to patients and their relatives in their communities. HBHC refer to palliative care. Palliative care can be defined as "a combination of active and compassionate therapies intended to comfort and support individuals and families living with a life threatening illness" (WHO, 2000). It is aimed to improve the quality of life for patients at the end of life by relieving symptoms and pain, enabling people to die in peace with dignity and following their wishes (WHO, 2002).

### **2.3. Healthcare Service Providers and Recipients**

Services in the healthcare sector are provided by different providers. Private healthcare sector provides high quality healthcare services in hospitals, clinics and other specialised units such as laboratory, paediatrics, surgery, cardiology, dentistry, and optometry (Western Cape Department of Health, 2009). These services are offered by general practitioners, specialised doctors, nurses (professional and nursing assistants), physiotherapists, dieticians, psychiatrist, pharmacists to mention a few.

Public healthcare sectors have hospitals, maternity hospitals, midwife obstetrics units, psychiatric hospitals, rehabilitation centres, reproductive health facilities, specialised health care facilities, tuberculosis (TB) hospitals, tertiary hospitals and community healthcare centres (Western Cape Department of Health, 2009). In primary healthcare facilities health workers that provide healthcare service are mainly nursing assistants, few professional nurses and doctors. In facilities where there are no doctors and pharmacists, the nurses diagnose and prescribe medication for minor ailments (Western Cape Department of Health, 2009).

In HBHC the care service is provided and supported by NGO's, CBO's, FBO's and hospices (Department of Health, 2001). These organisations are responsible for the overall supervision, co-ordination and administration. These organisations then recruit nurses, caregivers, coordinators, administrators and volunteers. According to the Kenyan Ministry of Health (2002), entry into the home-based care system is facilitated by several individuals and groups which include Voluntary Counselling and Testing (VCT) programs, preventative services such as Prevention of Mother to Child Transmission (PMTCT), caregivers or Community health workers, counsellors, spiritual advisors, health facilities and people who care about the patient.

### **2.3.1. Clinicians**

Clinicians in HBHC are the personnel that work directly or indirectly with patients. These include doctors, professional nurses and caregivers. There are other people who form the HBHC team such as counsellors, spiritual advisors and social workers who are not clinicians but are an important part of the care of the patient (Kenyan Ministry of Health, 2002). The professional nurses are responsible for diagnosing the patients in some cases and developing care plans for them and monitoring the progress the work of caregivers to ensure that patients get quality care (Ncama, 2007). Caregivers work directly with the patients and visit them at their homes.

### **2.3.1.1. Caregivers**

Caregivers can be formally trained nurses to semi-trained or informal carers such as family, friends, neighbours and members of the community with family members being the primary caregivers (National Department of Health, 2002). When patients are discharged from hospitals they usually do not have people to take care of them, the primary caregivers do not have the necessary expertise needed to take care of the patient or they are scared of being infected or simply do not care. Therefore the patients require the help of the caregivers (National Department of Health, 2002). A variety of terms such as Community caregivers, HBHC Carers, Community-based Health Worker, and Onompilo are used to describe caregivers (National Department of Health, 2002).

The main role of the caregiver is to provide basic nursing and palliative care to patients in their homes. In rural and poor communities it is uncommon to find nurses working as caregivers. Nurses occupy leadership and management positions in HBHC providers (Van Zyl, 2011). Caregivers visit patients on a daily basis, often walking long distances in good or bad weather conditions. They do a range of activities which include post-operation, chronic care and palliative care (National Department of Health, 2002). They also provide psychological and emotional support such as counselling, prayer and companionship, advice about social grants, training the family members how to care for the patient, basic health education and awareness (National Department of Health, 2002; Mkandariwe & Muula, 2005).

Caregivers also identify the needs of the patients and their families, provide support, basic medication, supplies and nutritional supplements where needed, assist in the referral to other levels of professional services such as hospitals, clinics, private doctors and hospice programmes if needed and identify the patients and children in need and refer them to HBHC centres. They usually work in communities where they live and are motivated to do the work in these communities.

There are a number of aspects that motivate caregivers to provide the care to the needy. Mkandariwe & Muula (2005) classify these as intrinsic and extrinsic factors. Intrinsic factors are the factors that are within the caregiver such as feelings of compassion, humanity, and religious convictions (Mkandariwe & Muula, 2005; Akintola, 2010; Gupta, Pillai & Levy; 2012). The intrinsic factors also include self-growth, the feeling of being useful and needed, personal (emotional and psychological) development on the job; they also derived satisfaction from community members taking a liking for them and expressing a need for their services” (Akintola, 2010; Koener, Kenyon & Shirai, 2009). Also the sense of fulfilment when the caregivers perform their care giving duties and making friends with the patients and their families forms part of the intrinsic factors.

Extrinsic factors are the factors that occur outside the caregiver such as expected opportunities (such as getting a permanent job within HBHC) and monetary benefits (Mkandariwe & Muula, 2005; National Department of Health, 2002). Extrinsic factors also include appreciation and recognition shown by patients and community members. The caregivers get motivated when the services they render make their patients happy (Koerner, Kenyon, & Shirai, 2009; Gupta, Pillai & Levy, 2012). The greatest sources of extrinsic factors are skills and competencies acquired from training and experience while caring for their patients, and caregivers' ability to make a difference in the community.

Many caregivers in South Africa are not getting paid for providing the care service to the sick (Mkandariwe & Muula, 2005). They act as volunteers because they feel they are assisting God by caring for the sick and to them care giving “benefits are not monetary here on earth but rather spiritual in heaven” (Mkandariwe & Muula, 2005). Some do it because they want to use their time effectively by giving back to their communities. Few caregivers are employed and paid by the NGOs which receive funding from Department of Health and Department of Social Development.

“NGOs employ caregivers directly or channel stipends from government departments to caregivers” (National Department of Health, 2002). Remuneration varies from a stipend of R500 and a salary of R2000 per month (National Department of Health, 2002). According to National Department of Health (2002), caregivers employed by the Hospice Association of South Africa are paid between R1200 to R1750 without benefits. Some Hospices pay an additional R250 for travel allowance. Hospices associated with the Provincial Administration support of caregivers pay the Department of Health compensation of R620 per month (National Department of Health, 2002).

### **2.3.2. Administration**

Administration in HBHC is done on national, district (provincial) and local (community) levels. According to WHO (2004), at the national level of policies needed to guide the HBHC programme are developed. The national level is responsible for “allocating resources, financing and supervising organisation and management” of the programme (comprising monitoring and evaluation) as well “developing human and material resources and allocating them based on clearly defined priorities” (WHO, 2004a). The district or provincial level allocates resources according to “clearly defined priorities set by the national administration” and also monitor HBHC quality standards (WHO, 2000a).

In local or community level culture, norms, standards and leadership of the community organisation plays a major role in the HBHC program. Strategies that promotes effective leadership and encourage community involvement in planning and implementing HBHC should be in place (WHO, 2004a). All the relevant stakeholders such as caregivers, ill people, health workers, social workers, volunteers and members of the community and leaders should be involved from the beginning and ensure the program is sustainable and successful (WHO, 2004a). The HBHC program is also integrated with other community services, agencies and local health facilities (WHO, 2004a).

Within the organisation all parties work together towards the success of the HBHC programme. Caregivers collect statistics about health and social issues in the communities. The administration staff ensures that all the statistics are done and that all caregivers' reports are incorporated in monthly reports to funders and government (Van Zyl, 2011). They are responsible for the overall management and dissemination of information in HBHC (National Department of Health, 2002). They play a vital role as all the activities in HBHC are dependent on data and information.

### **2.3.3. Care Recipients**

In South Africa only about 7 million of the country's population can afford to go to private hospitals, clinics and doctors and the rest of the country's patients use public healthcare sector (SA Human Rights Commission, 2009). In many peri-urban areas and rural areas people are faced with many problems particularly poverty. About more than 50% of the people live in informal housing and a large number of them live below the \$2 poverty line (Statistics South Africa, 2011). Most people are uneducated and unemployed. The small numbers of people who are educated move to big cities to find work and better their lives. The rest of the population rely mostly on social grants, for pensioners and the disabled, and they live in areas that lack basic services such as water, electricity, decent roads and flushable toilets (Van Zyl, 2011). The communities have high rates of crime, people living with HIV/Aids, TB and other poverty-related illnesses. They do not have the financial means to go to private healthcare facilities. These people visit community health clinics and local hospitals and often require long-term care provided by HBHC (Van Zyl, 2011).

HBHC requires the resources, skills, time, energy and funds of the communities and governments. It is connoted that health is the outcome of complete social and economic development of the community (Department of Health, 2001). For that reason all the requirements and challenges of HBHC cannot be met by a single unit. Collaboration between people is crucial in the success of HBHC endeavours. "Care in a community must become care by the community" (Department of Health, 2001). In the same way HBHC in South Africa does not focus only on the patients.

Family members have needs that require HBHC service. According to the Department of Health (2001), the “HBHC programme should be directed to healthy people, elderly persons that are frail or at risk, people with moderate to severe functional disabilities, people recovering from illnesses and in need of care, terminally ill persons, people living with HIV/AIDS or any incapacitating disease and any other disadvantaged group/person such as orphans and people in crisis”. This shows that not only patients have needs. Family needs may include social and psychological care. The needs of the patients also known as clients include physical care, psychological care, palliative care and spiritual activities. Often patients particularly HIV/AIDS patients and their family members need HBHC services to cope with the illnesses therefore people-centred healthcare becomes necessary.

According to the WHO (2007), healthcare should move from patient-centred approach to people centred approach. People-centred approach recognises that before people become patients, they need to be empowered in promoting their own health (WHO, 2007). The WHO (2007) emphasizes the importance of reaching out to all people, to families and communities beyond the clinical setting. HBHC mostly uses the principles of people-centred healthcare by playing an important role in educating people and families about different illnesses and to how to prevent them through the public health interventions such as health promotion outside clinical settings.

Many HBHC facilities do awareness campaigns, door-to-visits and workshops and educate different people about health issues. These health promotion efforts reach some people in the general community long before they become patients and enter a clinical health care facility. The family members become care recipients and heavily involved during the care of the patients. During the initial stages of the Socio-Tech Project at CPUT, it was observed that family members often sat in and participated when caregivers provide care services to patients.

## **2.4. Indigenous Knowledge (IK)**

IK is not a new term; researchers all over the world have been looking at it for past two decades. Many studies are being conducted on Indigenous Knowledge (IK) worldwide and many countries have started developing Indigenous knowledge systems (IKS). These IKS used to preserve IK that is slowly disappearing (DST, 2004). Many organisations such as the World Bank, United Nations (UN), International Council of Science (ICSU), World Intellectual Property Organisation (WIPO), United Nations Educational, Scientific, and Cultural Organization (UNESCO), United Nations Development Program (UNDP), International Federation of Library Association and Institutions (IFLA), governments and many scholars are continually looking at ways which IK can be used for development all over the world. Countries such as Canada, India and Australia have been involved in many IK and IKS development projects.

Countries in sub-Saharan Africa have are also involved in many IK projects that are aimed to preserve and disseminate IK for development purposes to reduce poverty (World Bank, 1999). The IK development projects are done in agriculture, healthcare, food preparation, education and natural resource management, health practices and prevention (medical technology) (World Bank, 1998; Msuya, 2007; Sukula, 2006). IK practices enable the integration into development work, provides problem solving approaches for local communities especially the poor (World Bank, 1998) and acts as a significant basis for local level decision making in all areas relevant to development (Mwantimwa, 2008).

IK is central to sustainable social and economic development. Proper IK management can provide practical tools for poverty alleviation; sustainable development and empowerment to communities (UNESCO, 1998; Lodhi & Mikulecky, 2010). In South Africa the Department of Science and Technology (DST) introduced the IK Systems Policy which covers integration of IK in education and the National System of Innovation of South Africa. The country's IKS is developed and maintained by indigenous peoples and spread or diffused through the lives and beliefs of a large proportion of the country's population (DST, 2004). Many other government departments in the country such as Department of Trade and Industry (DTI), Department of Education (DoE), Department of Land Affairs (DLA),

Department of Arts and Culture (DAC) also support the initiatives of IK preservation as IK is at risk of extinction due to Westernisation and use of technology (DST, 2004).

There is no simple definition of what IK is. IK can be defined as "a complete body of knowledge, know-how and practices maintained and developed by peoples through generations, generally in rural areas" (World Bank, 2009). According to Flavier, De Jesus & Mavarro (1995), IK is "is the information base for a society, which facilitates communication and decision making; it is dynamic and is continuously influenced by internal creativity and experimentation as well as by contact with external systems". Indigenous knowledge is unique to a given culture or society, the basis for local level decision making in agriculture, healthcare, food preparation, education, natural resource management and a host of other activities in rural communities" (Warren, 1991).

The National Research Foundation – NRF (2003) defines IK as a "complex set of knowledge and technologies existing and developed around specific conditions of populations and communities indigenous to a particular geographic area". Grenier (1998:1) defines IK as "the unique, traditional, local knowledge existing within and developed around the specific conditions of women and men – indigenous to a particular area". According to Rajasekan, Martin & Warren (1993:25), IK is "the systematic body of knowledge acquired through the accumulation of experiences and intimate understanding of the environment of a given culture". Rajasekan, Martin & Warren (1993) further state that IK can be traditional or local and it influences decision-making in local areas. According to Sillitoe (2010), the IK initiatives is an effort to provide "local voices and practices" with more prominence in development contexts but it is not any easy task because people's ideas of what forms knowledge differ.

UNESCO's Best Practices Using Indigenous Knowledge, warns that it is exceedingly difficult to define IK: "It is only when we try to translate these local practices into western terms that researchers are confronted with the need to choose a certain definition, and they see how difficult it is to give voice to a worldview, which is sometimes completely different from their own" (Boven & Morohashi, 2002:12). According to (Lodhi & Mikulecky, 2010), IK has several characteristics that differentiate it from other forms of knowledge. These are "originating within the community, maintaining a non-formal means of dissemination, collectively owned, developed over several generations and subject to adaptation, as well as imbedded in a community way of life as a means for survival" (Lodhi & Mikulecky, 2010). The exchange of IK takes place through personal communication and demonstration (Lodhi & Mikulecky, 2010) for example caregiver to caregiver or caregiver to patient in HBHC.

Indigenous knowledge is an important element of the "social capital" of the poor; their key asset to invest in the struggle for survival, to produce food, to encompass shelter or to enable them to take control of their own lives (World Bank, 1999). Owing to dynamic nature IK changes its character according to the needs of people and gains vitality from being deeply entrenched in people's lives (Mugabe, 1998). According to the DST (2004), IK use in sectors such as agriculture can contribute to the economy. IK still plays a vital role in sustaining the lives of many South African particularly in rural areas where people use traditional medicines and traditional agriculture. However Sillitoe (2010) states that even though IK has had some success in development, it is still difficult to come up with global solutions as IK varies from one place to another. Batchelor (2011) argues that IK has great value in communities particularly rural areas and these should be explored integrated in education and other sectors.

For the purposes of this examination, indigenous knowledge can be defined as the local knowledge that is unique to a given cultural group or society (Aluma, 2004; Mwantimwa, 2008) and is not seen as traditional knowledge but rather local knowledge. IK is basically tacit knowledge that is not easily collected or organised (World Bank, 1998). According to Van der Wilden (2002), tacit knowledge is based on experience and expertise, reflects on ways of doing things and is used when making sense of things. Van der Wilden (2002) further states that tacit knowledge is transferred from one person to another orally and is usually not documented.

The case is the same in HBHC in South Africa, caregivers' IK is based on their experiences and expertise shown in the way they understand and use data elements when they provide a care service.

## **2.5. Information in Healthcare**

Information is one of the key elements in healthcare. It is used for several reasons from decision making at the point of care to health policies. There are several ways the information is recorded, presented, evaluated and analysed. This section defines terms such as data, information and knowledge and outlines how information is recorded, presented and used in healthcare particularly in HBHC. It also looks at how Information and Communication Technologies (ICTs) are used in healthcare

### **2.5.1. Information and Information management**

Data is "the representation of facts as text, numbers, graphics, images, sound or video" (Data Management Association, 2009:2). Data can be a number, word or letter without context (Uriarte, 2008). Uriarte (2008) defines information as "a relationship between data that is dependent on context for its meaning and with little implication for the future". Information is data in context (Data Management Association, 2009). Data without context is meaningless therefore data users need to create meaningful information by interpreting the context around data. Knowledge is the understanding, awareness, cognizance, and the recognition of a situation and familiarity with its complexity.

Knowledge is information in perspective, integrated into a viewpoint based on the recognition and interpretation of patterns, such as trends, formed with other information and experience (Data Management Association, 2009). Knowledge may also include assumptions and theories about causes. When information is further processed it may become knowledge. Uriarte (2008) states that information is further processed when there is a pattern relation existing among data and information and when the patterns and their implications are realised and understood, then this collection of data and information becomes knowledge. Unlike information, knowledge is not context dependent, it tends to create its own context.

## **2.5.2. Records**

Patient data is any data collected about the patient. This includes diagnosis, patient history, patient details, allergies, symptoms, treatment or medication, intervention and test results (Van Zyl, 2011; WHO, 2002). In HBHC patient data is collected mainly by caregivers who play an important role in data and information flows (Delen, 2010). This data is used by managers to check patient progress and update care plans. Patient data is also used in managerial reports to know the statistics, care needs of patients and to request funding in order to provide better care to patients (WHO, 2002). This patient data is captured in patient records which are discussed below.

### **2.5.2.1. Paper-based systems**

Most HBHC providers are using paper-based patient records. A patient record can be defined as a “repository of information about a single patient, generated by health care professionals as the direct result of interaction with the patient or his relatives” (Tange, 1995). Using paper-based patient records has both advantages and disadvantages. The advantages are caregivers are familiar with the paper-based records and easily moveable to the bedside (Tange, 1995, Hippisley-Cox et.al, 2003). According to Tange (1995), paper-based patient records allow caregivers to decide which patient data to record, the level of detail, which words to use to describe the content and the order in which to record data. Paper-based patient records can be browsed through easily. However there are number of

disadvantages of using paper-based patient records in healthcare particularly in HBHC.

One of the disadvantages is paper-based patient records are often incomplete or incorrectly filled in. Another disadvantage is that caregivers in HBHC are usually exposed to bad weather such as rain, wind and sunlight while carrying these patient records. These patient records get destroyed and the data is not easily readable. The patient records also get lost due to constant movement of the caregivers. All these issues have a negative effect on overall patient care.

#### **2.5.2.2. Data Recording**

Questions regarding data recording in HBHC were asked from the literature. The questions are:-How and why is the data recorded? In what form is data recorded? What is the purpose of data recording?

There are different types of care records used in HBHC. These include care plans, home-patient care records, caregiver home visit forms and tally sheets (Van Zyl, 2011; Delen, 2010). Caregivers need to fill in these forms every time they are with patients. Each form has a particular purpose. The home visit form is used by the caregiver to show who they visited, on which day, how long they spent at the patient's home, and what kind of assistance they provided to the patient (Van Zyl, 2011). The patient or family member needs to sign the form to confirm that the caregivers were in fact present at the home and administered care. The home-patient care record is composed of the care plan, patient care report and the supplies order form.

The care plan is given to the caregiver by the HBHC provider and it shows what type of care is needed by the patient (Van Zyl, 2011). The patient care report is used to show which day did caregiver visit and the type of care administered (Delen, 2010). The supplies order form is used to request the supplies needed to care for the patient. The home-patient care record is left at the patients' home so that the family members can see the type of care given to the patient and for government officials to see if the caregiver is doing the work and to provide the needed supplies. At the end of each day, caregivers need to calculate the total number of the patients they saw

and the different treatments they administered. These statistics are sent to the area coordinator who then compiles care tally sheets for the area.

#### **2.5.2.2.1. Data elements**

There are several definitions of data elements found in the literature. Some definitions relate to computer science and some to healthcare. The technical definition of a data element according to ISO/EIC 11179 standard is “a unit of data for which the definition, identification, representation and permissible values are specified by means of a set of attributes”. In other words a data element is a basic building block for data models and each data element is specified in terms of a definition, a name, a representations and a set of valid values Logan & Gorman (2001). ISO/IEC 11179-1 further states that a data element then is a single unit of data that in a certain context is considered indivisible. It represents a single fact about a type of object (object class) in the natural world (ISO & IEC, 1999).

According to Logan & Gorman (2001), a data element can be defined as a piece of information that separately adds meaning in the patient record. All the care forms have data elements such as patient name, address, blood pressure, temperature, pulse, category etc.

### **2.6. Use of Information and Communication Technologies (ICTs) in Healthcare (E-HEALTH)**

WHO has taken a lead in eHealth and encourages countries especially developing countries not to be left out as the world is now being digitalised (WHO, 2004b). WHO (2004) defines e-health as “the combined use in the health sector of electronic communication and information technology (digital data transmitted, stored and retrieved electronically) for clinical, education and administrative purposes, both at the local site and at a distance”. In the healthcare industry the use of ICT systems such as Electronic Health Records (EHR) has a potential to reduce process inefficiencies, control spiralling healthcare costs, improve the quality of care and patient safety (Edwards et. al., 2008). Due to the number of disadvantages of using paper-based patient records, South African Healthcare is now moving from paper-based patient records to EHR.

EHR is a “repository of patient data in digital form, stored and exchanged securely, and accessible by multiple authorised users” (Hayrinen, Saranto & Nykanen, 2008). “It contains retrospective, concurrent, and prospective information and its primary purpose is to support continuing, efficient and quality integrated health” (Hayrinen, Saranto & Nykanen, 2008). EHRs are mainly used for setting objectives and planning patient care, documenting the given care and assessing the outcomes of care (Hayrinen, Saranto & Nykanen, 2008). The information captured on the EHR is also used in the decision-making process in the patient care and supports decision-making in management and health policy (Hayrinen, Saranto & Nykanen, 2008).

South Africa has started implementing an EHR and other eHealth solutions such as Hospital Information Systems (HIS), District Health Information Systems (DHIS), to improve the national healthcare sector. According to IT-Online (2007), eHealth solutions are intended to improve access to healthcare, quality of care, prevention of illnesses, health promotion and better and affordable healthcare. There have been many problems with the adoption of EHR in South Africa particularly in rural areas as there is no uniform approach to healthcare, lack of standardisation and integration between health information systems, geographic distribution, faulty ICT infrastructure and identification of a unique patient identifier (Ruxwana, Herselman & Conradie, 2010).

Use of ICTs has been introduced in HBHC in South Africa. Several institutions, researchers, developers and DOH are looking at ways to improve the countries HBHC using ICTs. There many projects under way on developing mobile applications, systems, repositories and records for HBHC workers and stakeholders. HBHC patient care records are currently not standardised. An example of such projects is conducted by SAFIPA in collaboration with CPUT, UP and NMMU is working on many projects to improve HBHC (SAFIPA, 2010). CSIR and researchers from Delft University conducted a study on how HBHC in African rural communities may be supported using Unstructured Supplementary Service Data (USSD) technology (Wouters, Barjis, Maponya, Maritz & Mashiri, 2009). It is hoped that this study may contribute towards an electronic Care Record for HBHC.

EHR in HBHC can be composed of several data components such as daily charting, medication administration, physical assessments, care plans, admission notes, referrals, physical examination, symptoms, lifestyle, diagnosis, tests, treatment and medication, immunization, intervention and supplies provided.

## 2.7. Conceptual Framework

A conceptual framework can be described as a “set of broad ideas and principles taken from relevant fields of enquiry and used to structure a subsequent presentation” (Reichel & Ramey, 1987). According to Camp (2001), a conceptual framework is a structure of what has been learned to best explain the natural progression of a phenomenon that is being studied. It aims to help the researcher to develop and communicate the “awareness and understanding” of the situation under study (Smyth, 2004).

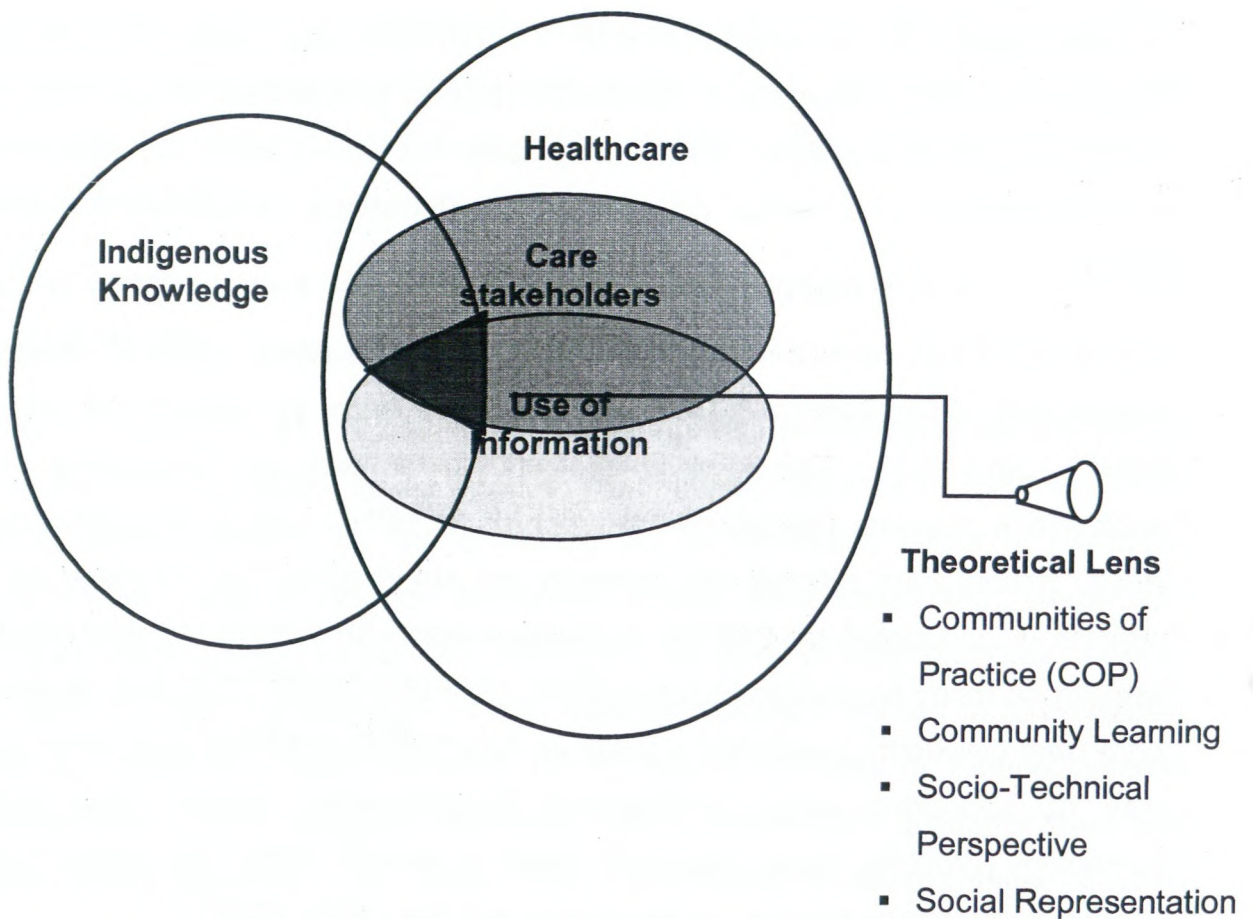


Figure 2.1: Framework for caregivers' IK use in HBHC

When clearly formulated the conceptual framework has a potential usefulness in providing a layout of the research and helping the researcher make sense of the findings (Smyth, 2004). It is used as a starting point of reflection about the research and its context. A conceptual framework consists of key factors, the variables and presumed relationships among them (Miles & Huberman, 1994).

The framework (Figure 3.2) draws on various aspects of indigenous knowledge theory and how it relates to the HBHC sector, care stakeholders and the use of information in health practice. It explores the intersection of indigenous knowledge, care stakeholders and health information practice. The framework uses communities of practice, socio-technical approach, community learning and social representation as lenses to view and analyse the interaction with information by caregivers. In other words how care stakeholders (that is caregivers) use of information in healthcare, particularly in HBHC and how indigenous knowledge influences this. There are many views given by different authors regarding indigenous knowledge and in the healthcare sector.

HBHC involves several stakeholders: patients, caregivers, doctors, nurses and administrators. These stakeholders are receivers, providers and facilitators of healthcare services. It is imperative that care providers use information and knowledge to provide quality care services. Indigenous knowledge theory and practice relates to many areas of healthcare such as care provision, traditional medicines, and traditional healing. Different care stakeholders in different areas use the knowledge they have in decision making, problem solving, administering treatments and general care giving.

According to Dyck (2009), caregivers need to combine learned and new skills specific to care activity. Dyck (2009) further states that the care service provision blends together the knowledge of a person with the information on the particular aspect of care required and the aptitude of that person develops over time. In rural areas where HBHC centres lack resources, IK plays a major role during care provision. There are many studies that have been conducted regarding the use of IK and how it has been used by many generations particularly in resource-limited settings.

In HBHC this tacit knowledge or “know-how” is practiced and exchanged by caregivers, helping them to make decisions during service provision. This allows them to build relationships of trust with other caregivers. The trust and invested practice forms a successful connection between caregivers and creates a supportive environment for knowledge sharing. This process is called communities of practice (CoP) (Van der Wilden, 2002).

## **2.8. Theoretical lenses**

The four lenses socio-technical theory, CoP, social representation and community learning will be used to understand the data better. The socio-technical theory will be used to categorise the data by looking at the technological, social and environmental aspects that take place in HBHC. The caregivers are influenced by these factors when they carry out their work and how they use and understand the forms and data elements on them. CoP, social representation and community learning will be used to describe caregivers’ indigenous knowledge and how this knowledge is disseminated.

### **2.8.1. Socio Technical Theory**

The social technical approach has been used recently in redesigning systems. Many researchers including Avgerou and LaRovere (2003) have researched and contributed to the literature of the importance of looking at both technical and social aspects during system development. The socio-technical system approach assumes an “organisation or an organisational work system as a socio-technical system”. This means that the work system is made up of both social and technical aspects (Bostrom & Heinen, 1977). The theory focuses on people, technology and the work. HBHC is seen as a socio-technical system with people, technology and the environment. When people do the work they interact with technology and their social aspects influence the way and how they interact with it. Also the environmental aspects have an influence on how work should be done.

## 2.8.2. Communities of Practice

A community of practice is “a group of people who share a common concern, a set of problems, or interest in a topic and who come together to fulfil both individual and group goals” (Wenger, McDermott & Snyder, 2002). “CoP are groups of people who share a passion for something that they know how to do, and who interact regularly in order to learn how to do it better” (Wenger, 2004). CoP usually focus on ‘sharing best practices’ and ‘creating new knowledge’ to improve a domain of professional practice (Wenger, 2004). On-going interaction is an important part of this. A community’s specific purpose and goals inform the appropriate activities and technologies that should support it.

Today, organisations, workgroups, teams, and individuals work together in one way or another and the collaboration between them is progressively important (Cambridge, Kaplan and Sute, 2005). Wenger, McDermott and Snyder (2002) offer several reasons why communities are important. These reasons are

- Communities connect people who are unlikely to interact often or interact at all
- Communities provide a shared setting where people can communicate and share information, stories and experiences in way that build trust, understanding and insight.
- Communities enable a discourse between individuals who come together to explore new possibilities, solve challenging problems, and create new, mutually beneficial opportunities.
- Communities encourage learning by being ‘a place’ for communication, mentoring, coaching, and self-reflection.
- Communities capture and disperse existing knowledge to help people improve their practice by providing a forum to identify solutions to common problems and a process to collect and evaluate best practices.
- Communities introduce collaborative processes to groups and organizations as well as between organizations to encourage the free flow of ideas and exchange of information.
- Communities help people to organise around purposeful actions that deliver tangible results.

- Communities generate new knowledge that assist people to transform their practices to accommodate needs and technology changes.
- Communities enable discourse between people who meet to explore new possibilities, solve problems and create new opportunities that benefit everyone.

A CoP helps NGOs and HBHC centres come up with new and better ways to carry out their tasks. HBHC caregivers have passion for their work; they meet regularly to share the problem they are faced with and come up with solutions as a community. CoP relates to social representation and community learning, which are also lenses that have been used in this study to look at the data.

### **2.8.3. Social Representation**

Social representation can be defined as a “system of values, ideas, and practices that establish a consensual order among phenomena and enable communication to take place among the members of a community by providing them with a code for social exchange” (Walmsley, 2004). Social representation theory focuses on the belief that “psychological states are socially produced and that our representations determine our reactions” (Walmsley, 2004). According to Walmsley (2004), representations are understood to be social creations and therefore a component of social reality. He further states that “social representations also show a common sensible understanding of the social world”. Social representations are placed together during action and communication between people in a particular community and are a precise and clear manner of “understanding and communicating” what is known already (Walmsley, 2004, Moscovici, 1984). Social representations “show the practical, everyday knowledge of the ordinary person rather than expert or scientific knowledge” and “structure our perception of social reality” (Walmsley, 2004).

“A representation is product of processes of mental activity through which an individual or group reconstitutes the reality with which it is confronted and to which it attributes a specific meaning” (Walmsley, 2004; Abric, 1994). A representation is more than just an indication of that reality and it also provides a “meaningful organization” of reality and functions as a “system of interpretation” that governs relationships between individuals and their physical and social environment. Representations determine behaviour and practice then operate as “guides for

action” (Abric, 1994). “The social representations perspective recognises human beings as thinking persons, capable of asking questions, seeking answers, and, in general, thinking about life” (Moscovici, 1984). In HBHC caregivers use their minds to solving problems they encounter as individuals and on their day to day activities. They also transform the ideas and develop ways in dealing with the society at large.

#### **2.8.4. Community learning**

In HBHC caregivers and the communities where they live understand things in a certain way. The community influences how the people see and understand things. Caregivers learn certain practices from their communities and use these practices and understanding in their daily activities. Researchers refer to community learning.

#### **2.9. Conclusion**

Literature shows that the caregivers' IK and use of data elements in HBHC in South Africa is a research area that is not largely explored. The chapter looked at what other researchers have written about healthcare, HBHC, caregivers, the use of information, indigenous knowledge and data recording. Several topics that are important for the study were discussed in this chapter. The next chapter looks at the research methodology.

## **CHAPTER THREE**

### **3. Research Methodology**

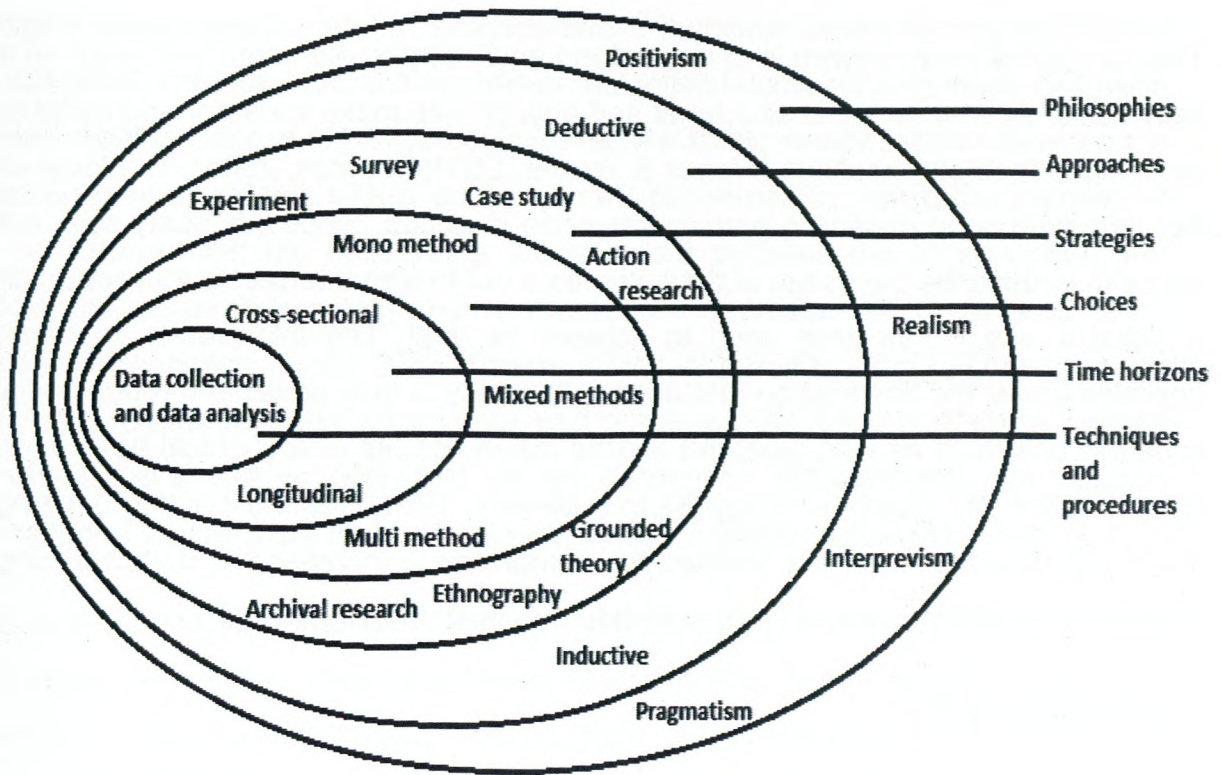
#### **3.1. Introduction**

The research problem emphasizes the need to investigate how caregivers use and understand data elements in HBHC. To ensure that the objectives of the study are met research methodology has to be clear and suit the purpose. In this chapter the ontological; and epistemological stance and the research approach are discussed. The chapter also looks at how the cases were selected; the methods used for data collection, data analysis and interpretation and ethical issues around the study.

#### **3.2. Research Methodology**

Deciding which methodology to use in research is one of the most difficult and daunting tasks for researchers, particularly novice researchers. Saunders, Thornhill & Lewis (2009) gave a suggestion in their research onion on the steps researchers can follow to make this task easier. These steps include philosophies, approaches, strategies, choices, time horizons and techniques and procedures as shown in Figure 3.1. This may seem simple but other researchers have a different opinion.

Following the research onion the methods used for data collection are in-depth interviews, focus groups, participant observation and document analysis. The study uses cross sectional time horizon. Cross sectional research time horizon assumes collection of data in more than one case at a single point in time and the data is then analysed to look for patterns of association (Shozi, 2012; Bryman & Bell 2007). The other aspects such as philosophy, strategy, approach are discussed in the sections below.



**Figure 3.1: Research Onion (Adapted from Saunders, Thornhill & Lewis; 2009)**

This study is qualitative and seeks to explore how caregivers use data elements in HBHC. It also identifies the common data elements and the relationship between data elements in different communities. Qualitative research is a research that aims to gather "rich descriptive data" regarding a specific phenomenon or context in order to develop an understanding of what is being observed or studied (Maree, 2007). "Qualitative research is also concerned with understanding the processes and social and cultural contexts which underlie various patterns" (Maree, 2007; Meyers, 2009). There are several perspectives of qualitative research. These include positivist, critical and interpretive approaches (Maree, 2007; Voce, 2004; Meyers, 2009). Interpretive approach that has been used for this study is discussed below.

### **3.3. Interpretive Research**

The purpose of interpretivism is to understand and interpret elements that occur on a daily basis, as well as social structures and how people make sense of and attribute meaning to their surroundings (Woods & Trexler, 2001; Thomas, 2006). The focus of this paradigm is on observing participants while in action. Since this study does not only aim to describe the usage of data elements but to also interpret it, this approach is suitable and it has been used to achieve its goal. The Interpretive approach operates under the assumption that access to reality is only possible through social constructions such as language and shared meanings. Its philosophical base is on hermeneutics and phenomenology (Klein & Meyers, 1999; Gummesson, 2003). Using the interpretive approach has enabled the researcher to increase her understanding of the important things about the use of data elements in HBHC, South Africa.

### **3.4. Research design**

There are a number of research designs used in qualitative research. These include historical research, action research and case study research to mention a few. Case study research which is suitable for this study is discussed below.

#### **3.4.1. Case study research**

A case study can be defined as “an empirical enquiry that investigates a contemporary phenomenon within its real-life context especially when the boundaries between phenomenon and context are not clearly evident” (Yin, 2003). According to Maree (2007), case study research is a study of events or a set of related events which seeks to explain and describe the event of interest. It uses multiple methods of data collection (Meyers, 2009; De Vries, 2005; Benbasat, Goldstein & Mead, 1987). Case study research is an important and widely used qualitative method in Information Systems (IS) research and other innovation fields as its findings can be applied in practice (De Vries, 2005; Shakir, 2002).

Case study research is suitable when “research and theory are at their early formative stages and for ‘sticky’, practice-based problems where the experiences of the actors are important and the context of the action is critical” (Benbasat, Goldstein & Mead, 1987). Case study is also considered a suitable research strategy when the proposed research deals with a contemporary phenomenon, which the researcher has no control over; the boundaries are not clear between the phenomenon and context, the research is mostly exploratory; and it addresses the “how” and “why” questions (Benbasat, et al., 1987; Baxter & Jak, 2008; Yin, 2003). Through case study research the researcher becomes part of the real-life world of practice, even if the researcher’s role is only that of an observer. Researchers can capture knowledge of practitioners to develop theories from it (Cepeda & Martin, 2005).

Case studies tend mostly to be based on qualitative data, as these provide a richer and deeper description. Klein and Myers (1999) define three types of case study depending on the research perspective, positivist, critical and interpretive. A positivist case study tests the theory, in an effort to increase the predictive understanding of formal propositions, measures variables, tests hypotheses and draws inferences from a sample to a given population (Lee, 1989). A critical case study aims at social critique and at being emancipatory, that is identifying different forms of social, cultural and political domination that may hinder human ability and improving case studies may have a character of being critical (Klein & Myers 1999). An interpretive case study attempts to understand phenomena through the participants’ interpretation of their context.

Interpretivists believe that multiple realities exist as subjective constructions of the mind. They see the world as socially constructed. They attempt to understand phenomena through analysing meanings people assign to these phenomena. Their research approach is inductive and concerned with discovering and interpreting social patterns (Klein & Meyers, 1999; Orlikowski & Baroudi, 1991; Walsham 1995).

Case study research has been used for this study because it uses multiple sources of evidence and it aims to provide answers to the how of the research question. This study is aimed at understanding how and why caregivers use data elements. Since the research area is under explored, case study research is a suitable approach. It has also allowed the researcher to examine the caregivers and their interaction with data elements in real life and caregivers' interpretations of data elements have been analysed.

### **3.4.2. Motivation and selection of case study sites**

To reiterate the aim of this study is to explore the relationships between, and approaches to, data elements in different HBHC providers and communities. This involves describing the use and presentation of data elements in different HBHC providers, the differences in the use of data elements in differing HBHC contexts and a core set of data elements for HBHC based on the care service provision in different communities. The study also identifies or defines an initial set of data elements for HBHC and a core set of data elements for HBHC from sets of care forms. Caregivers' indigenous knowledge of their interaction with data elements is also harnessed and captured in a knowledge base.

Over a period of one year, beginning in February 2010 three case studies were conducted in Western and Eastern Cape provinces. The three HBHC facilities were selected because of assumed easy access, the role they play in the communities where they operate, experience in health care service provision and their approval of the researcher's ethics. The researcher had developed a relationship with two of these facilities when she worked on Socio-Tech: Made in South Africa project the previous year where they were conducting studies on how home-based healthcare operates in South Africa. The first case is MIDA Health and Poverty Project, a HBHC centre in Dutywa, Eastern Cape Province. The second case was in Ixabiso Lomntu Community Health Centre in Ndakeni Location, Flagstaff, Eastern Cape Province. The third case is the Stellenbosch Hospice in Stellenbosch, Western Cape Province.

Stellenbosch Hospice and MIDA Health and Poverty Project were selected because of the relationship that they had with the Socio-Tech: Made in South Africa Project at the University during the first phase of the project. Access at the Stellenbosch Hospice was easy and the participants were very helpful. The researcher experienced some problems at first with MIDA Health and Poverty Project because of their expectations. The researcher together with the Home-based Healthcare Manager resolved the matter and the participants were eager to share their knowledge. Ixabiso Lomntu Community Health Centre was selected because the researcher wanted a different perspective of Eastern Cape Province HBHC and to see how caregivers use data elements in that community. Access was easy but there were fewer caregivers available for the interviews.

The three HBHC facilities play a big role in the communities where they are and they agree with the researcher's ethics. Initially the researcher wanted to have two HBHC centres in each province and at least one group of clinic caregivers. The clinic caregivers in Eastern Cape did not have time for interviews as they work with a large number of patients. YMCA was also considered but they do not have caregivers who speak Xhosa. In addition the researcher is Xhosa speaking and does not speak Afrikaans; therefore could not conduct interviews in English and lose that valuable information during translation. The plan was to have 11 participants (10 caregivers and one HBHC manager or coordinator) from each community.

### **3.4.3. Unit of analysis**

In this study, the unit of analysis is caregivers' interaction with data elements. This entails which forms are used in each area, who influences which and how forms should be used. As well how individual caregivers from three areas use and understand data elements when they provide the care service to the patients in their home. The study also looks at the patterns of use of data elements by caregivers that is the similarities and/or differences in all three cases.

### **3.5. Data Collection**

For this study qualitative data collection methods such as participant observations, interviews, focus groups and document analysis were used. These are discussed below.

#### **3.5.1. In-depth Interviews**

The in-depth interview is a qualitative research method that requires conducting exhaustive individual interviews with a small number of respondents to look into their viewpoints on a particular idea or situation (FHI, 2005a). In-depth interviews normally provide context to other data, offering a more complete picture of what happened and why. For this study, in-depth interviews have been used to uncover detailed information about caregiver's opinions and how they use data elements in HBHC. A total of 15 caregivers and two HBHC managers from two communities in the Eastern Cape were interviewed.

The caregivers were interviewed to elicit IK, how they use and understand data elements the different forms that they use, understand the context (the work they do, conditions where the caregivers work, challenges they are facing and the benefits of care giving). Two HBHC managers were interviewed to validate caregivers' responses and also to understand how the facilities choose data elements on the forms and who influences this. In-depth interviews have been used also been used in place of focus groups for the potential participants that are not included or uncomfortable to talk openly in a group or when the researcher wants to differentiate individual' views about the data element usage.

The most important advantage of in-depth interviews is that they provide detailed information on how caregivers use and perceive data elements in home-based healthcare than what was available through other data collection methods, such as document analysis. In-depth interviews also provided a more relaxed atmosphere for data collection and respondents felt more comfortable having a conversation with the researcher about their work and their interaction with data elements as they were done with individuals rather than in groups. In both provinces HBHC managers, coordinators and caregivers were interviewed. The managers in both provinces were interviewed to find out which forms they use and how they are used, to understand how their organisations select the data elements on the forms and why they use the data elements the way they do. All the interviews were conducted in Xhosa and then translated to transcribed and translated in English for the purpose of the research.

### **3.5.2. Focus groups**

A focus group is a qualitative data collection method where one or two researchers and a number of participants meet as a group to discuss a given research topic (FHI, 2005b). The major benefit of a focus group is that it elicits a lot of information over a fairly short period of time. A focus group was also useful for accessing a wide variety of views on HBHC caregivers IK practices and use of data elements.

A group of participants representing caregivers were selected in Idutywa, Flagstaff and Stellenbosch communities (in both Eastern and Western Cape provinces). Both experienced and novice caregivers were chosen as participants as they all possess knowledge about their interaction with data elements. Caregivers who have worked in HBHC for at least 6 months were more suitable as they have experience as to how the work is done and provided more information.

### **3.5.3. Participant Observation**

Participant observation is a qualitative method that aims to assist the researcher to learn and understand diverse participants' viewpoints (Maree, 2007). Participant observation is also helpful for acquiring "an understanding of the physical, social, cultural, and economic contexts in which study participants live; the relationships among and between people, contexts, ideas, norms, and events; and people's behaviours and activities – what they do, how frequently, and with whom" (FHI, 2005c).

Participant observation also helps researchers to discover important aspects for a thorough understanding of the research problem that were unknown or unclear when the study was designed. This is the great advantage of the method because participant observation helped the researcher not only to understand data collected through other methods but also to plan questions for those methods such as interviews, which provided the best understanding of the phenomenon being studied.

The researcher acted as a participant observer in two communities, observed and participated in caregiver's daily activities for two days. This was done so that the researcher can gain a better understanding of how data elements are used and why they are used in such manner. The researcher conducted participant observation in Ixabiso Lomntu Community Health Project for three days. Ixabiso Lomntu Community Health Project the researcher assisted the caregivers with basic activities at their hospice rooms with four patients. The basic activities included administering treatments and medication, checking how the patients are feeling and observing the environment where the patients were. During this time the researcher saw the way the caregiver use the forms to capture the patient data and the details of the care service in these two communities. In Stellenbosch the researcher walked with caregivers to several patients' homes but did not participate in caring for the patients. However she assisted in filling in the forms and observed while the caregivers worked.

#### **3.5.4. Document Analysis**

Document analysis, a qualitative data gathering technique was used. All the documents that provide information about the problem were gathered and analysed. These documents include both published and unpublished data sources such as HBHC reports, care plans, patient records, home visit forms and tally sheets and any document that shed some light to the study. Forms that are used by caregivers when they provide a care service in all different communities were made available to the researcher who then analysed them. The documents provided the researcher with background information about the data elements and helped the researcher to probe during interviews with caregivers when they left certain information out. The data elements on the forms were then captured in the knowledge base together with the information on how caregivers use data elements in HBHC.

#### **3.6. Data Analysis**

The data was interpreted through the process and practice of Hermeneutics. Hermeneutics is a general methodology for interpretation (Gummesson, 2003). Hermeneutics suggests that “we come to understand a complex whole from preconceptions about the meanings of its parts and their interpretations” (Klein & Myers, 1999). Hermeneutics is also concerned with the interpretation of non-lingual expressions of human life, where the researcher tries to translate tacit knowledge into words (Gummesson, 2003). Seven principles for interpretive research identified by Klein and Myers (1999) were used in Table 3.1.

**Table 3.1: 7 Principles for Interpretive Field Research (adapted from Klein & Myers, 1999)**

Principle	7 Principles for Interpretive Field Research
1	<p><b>The fundamental principle of hermeneutic circle</b></p> <p>This principle suggests that all human understanding is achieved by iterating between considering the interdependent meaning of parts and the whole that they form.</p>
2	<p><b>The principle of contextualisation</b></p> <p>Requires critical reflection of the social and historical background of the research setting, so that the intended audience can see how the current situation under investigation emerged.</p>
3	<p><b>The principle of interaction between the researchers and subjects</b></p> <p>Requires critical reflection on how the research materials (or "data") were socially constructed through the interaction between the researchers and participants.</p>
4	<p><b>The principle of abstraction and generalisation</b></p> <p>Requires relating the idiographic details revealed by the data interpretation through the application of principles one and two to theoretical, general concepts that describe the nature of human understanding and social action.</p>
5	<p><b>The principle of dialogical reasoning</b></p> <p>Requires sensitivity to possible contradictions between the theoretical preconception guiding the research design and actual findings ("the story which the data tell") with subsequent cycles of revision.</p>
6	<p><b>The principle of multiple interpretations</b></p> <p>Requires sensitivity to possible differences in interpretations among the participants as are typically expressed in multiple narratives or stories of the same sequence of events under study.</p>
7	<p><b>The principle of suspicion</b></p> <p>Requires sensitivity to possible "biases" and systematic "distortions" in the narratives collected from the participants.</p>

The data was analysed and interpreted by exploring at patterns and meanings to derive an understanding of how caregivers use data elements in practice. According to Gadamer (1976), the hermeneutic circle is made up of parts and the whole and both these terms need to be given an interpretation. Gadamer (1976) further states that the whole is composed of the shared meanings that emerge from the interrelations between parts. Data element usage by caregivers was analysed and interpreted to show the common usage between them to form a whole. The whole was therefore made of the core elements used in different communities. The captured IK was analysed to identify patterns of use in different communities.

### **3.7. Ethical considerations**

Indigenous knowledge represents a form of intellectual property and 'is owned' by those who express, exchange, and present it (DST, 2004). Certain regulations govern the collection, archiving and use of IK. In South Africa researchers are required to obtain written consent to use IK and it remains the property of the communities where it was collected. For this study the consent to collect, archive and use IK was obtained for all three cases. The research methods used when collecting indigenous knowledge were appropriate to the participants and did not have any negative impact on them, physically, emotionally or otherwise. The methods for data collection, data analysis and presentation of findings were explained to participants.

The study did not involve any unethical behaviour. All interviews and observational data collection was carried out in a sensitive manner to ensure that the dignity of participants was respected. Confidentiality has also been assured and no names, addresses or patient numbers will be revealed. Respondents were free to refuse to participate at any stage of data collection. All the names of the participants during home visits have been changed to protect the identities of the participants. The data collection was conducted in Xhosa which is the home language of the respondent to ensure comfort and ease of conversation. Written consent to use the data and IK was obtained. Consent forms were provided in English and verbally translated into the home language of the respondent.

There are a number of issues that the researchers should be aware of when collecting IK. HBHC facilities and NPOs particularly in Eastern Cape are under-resourced and under-staffed and they are continually. Participants and the organisations that they work for want to be involved in such projects and most of the time they want something in return for their knowledge and time. It is important that the researchers take the products or guidelines back to the communities so they can use this to improve the work they do.

### **3.8. Conclusion**

In this chapter, philosophical underpinnings were discussed. The study is qualitative and uses interpretivist approach. Interpretive case studies were used and three cases from Eastern and Western Cape Provinces were selected. Caregivers and HBHC managers from these three cases were chosen as participants. Four qualitative research methods were used namely in-depth interviews, focus groups, participant observations and document analysis. Prior data collection the researcher got approval to from the three cases. The next chapter looks at the findings.

## **CHAPTER FOUR**

### **4. Empirical Findings**

#### **4.1. Introduction**

The study was conducted in three Xhosa speaking communities in the Eastern and Western Cape Provinces of South Africa. The Xhosa language is the language of the Xhosa people. It is also one of the 11 official languages of South Africa and the main language among Xhosas in Eastern and Western Cape Provinces. The Xhosa cultural group has many sub groups such as abaThembu, amaBhaca, amaMpondo, amaXesibe, aMampondomise, amaBomvana which have their own dialects. The two communities in Eastern Cape are located in Flagstaff and Dutywa in the former Transkei area. HBHC centres in both communities are under-resourced and operate under difficult conditions such as lack of or insufficient funds, lack of trained personnel, poverty amongst patients, high rate of HIV/AIDS and other illnesses. The third community is Kayamandi in Greater Stellenbosch, Western Cape Provinces. Most caregivers working in the Eastern Cape Province are volunteers who want to better the lives of the people in their communities. All three communities are located within rural and peri-urban. These communities are faced with a number of socio-economic issues such as: poverty, unemployment, high rate of crime and lack of basic services.

Data collection was undertaken in order to help answer the research sub-questions detailed in Table 4.1. By answering these sub-questions it would in turn provide an answer to the main research question which guided this research undertaking.

**Table 4.1.1: Sub-Questions**

a. Which data elements are relevant to HBHC, and caregivers in particular?
b. How are data elements presented on different forms and reports in HBHC?
c. How does one capture or understand (indigenous) knowledge regarding how caregivers actually use data elements?
d. How are data elements used differently in different communities?

The question sets shown in Appendices A and B were prepared beforehand and were used as a guide by the researcher during the data collection. This chapter will present the findings from the three communities. The structure of the findings uses the themes in Table 4.2 below.

**Table 4.1.2: Interview Guidelines**

1. Who is the caregiver?
2. Data elements on the forms used in practice
3. Management of care service
4. Caregivers' perception of data elements
5. Caregivers' Challenges

**4.2. Data Collection**

Data was collected using document analysis, focus groups, interviews and participant observations. The focus groups were conducted in order to understand the context (that is the environment where the caregivers work), who the caregivers are, their education level, skills, training and experiences, their working environments as well as the challenges that they are faced with at work. These focus groups aided in raising important issues that the researcher needed to be aware of and probe on during individual in-depth interviews. In the Eastern Cape Province the questions mentioned in section 4.1 were asked during the interviews.

The interviews were largely focused on eliciting the data elements used in HBHC, the way the caregivers use data elements and caregivers' indigenous knowledge. Participant observations were conducted in the Flagstaff and Kayamandi communities. The researcher walked with the caregivers to the homes (and hospice patient rooms in case of Ixabiso Lomntu) and assisted them with care service provision to different patients. This was beneficial for the research as it allowed observation of: the kinds of environments in which the caregivers work, the severity of the patient illnesses, the challenges that the caregivers are faced with on a daily basis and additional activities performed by the caregivers that they did not mention during the interviews. The various forms used by caregivers during the provision of care services were collected for further analysis..

In Flagstaff area the provision of care services is managed by Ixabiso Lomntu Healthcare Centre with four caregivers and one HBHC manager (also known as the coordinator). These respondents were interviewed in a period of a week from the 5<sup>th</sup> to the 9<sup>th</sup> of July 2010. Participant observation was conducted for a day at the Ixabiso Community Health Centre (Hospice) during which time two elderly women, a disabled man and an ill child was cared for. In the Dutywa community only interviews were conducted due to the poor weather conditions, inaccessibility of transport to the rural areas. The time constraint prevented these issues from being resolved within the period of study. Eleven caregivers and the Coordinator were interviewed from the 22<sup>nd</sup> to the 25<sup>th</sup> of June 2010. In the Kayamandi community care services are provided by the Stellenbosch Hospice. In the Kayamandi community interviews, focus group and participant observation were conducted during the period of March 2010 to March 2011. The final data collection was done on the 4<sup>th</sup> to 7<sup>th</sup> March 2011. During this time the researcher interacted with caregivers and nurses who work in different areas.

#### **4.2.1. Role of Researcher**

The researcher submitted her research proposal as well as the Ethics Form, explaining the ethical issues on the research, to the Higher Degrees Committee (HDC). The ethics were approved by the Ethics Committee at the Cape Peninsula University of Technology (CPUT). The research was approved by the HDC and the researcher started work on the research. The researcher is an African, Xhosa speaking female. For the study it was important that the researcher was fluent in Xhosa, competent in the different dialects and had an understanding of the complexities of the language. The fact that the researcher is female helped make the caregivers comfortable during data collection as all the caregivers from the three cases were female.

The researcher obtained permission from the relevant authorities at the HBHC centres to conduct interviews and participant observations. The researcher scheduled appointments and prepared questions beforehand. The questions were used as a guide for the researcher to keep on track to the research objectives during data collection. During data collection the researcher acted as both an interviewer and participant observer. Gaining access to Stellenbosch Hospice was simple due to the pre-existing relationship with the researcher and the Socio-Tech Project also known as Kujali.

In Ixabiso Lomntu Healthcare Centre access was simple due to the managers who are always willing to assist students in gathering information for their studies. For MIDA Health and Poverty Project access was more difficult due to previous misunderstandings which the manager had with prior non-related researchers. Furthermore the manager wanted the HBHC facility to gain some form of benefit in exchange from providing any information. The researcher explained to the manager that the data was purely for study purposes and was then given permission to collect the data. The HBHC facilities in rural areas are under-resourced therefore managers are constantly looking for opportunities for funding and partnerships.

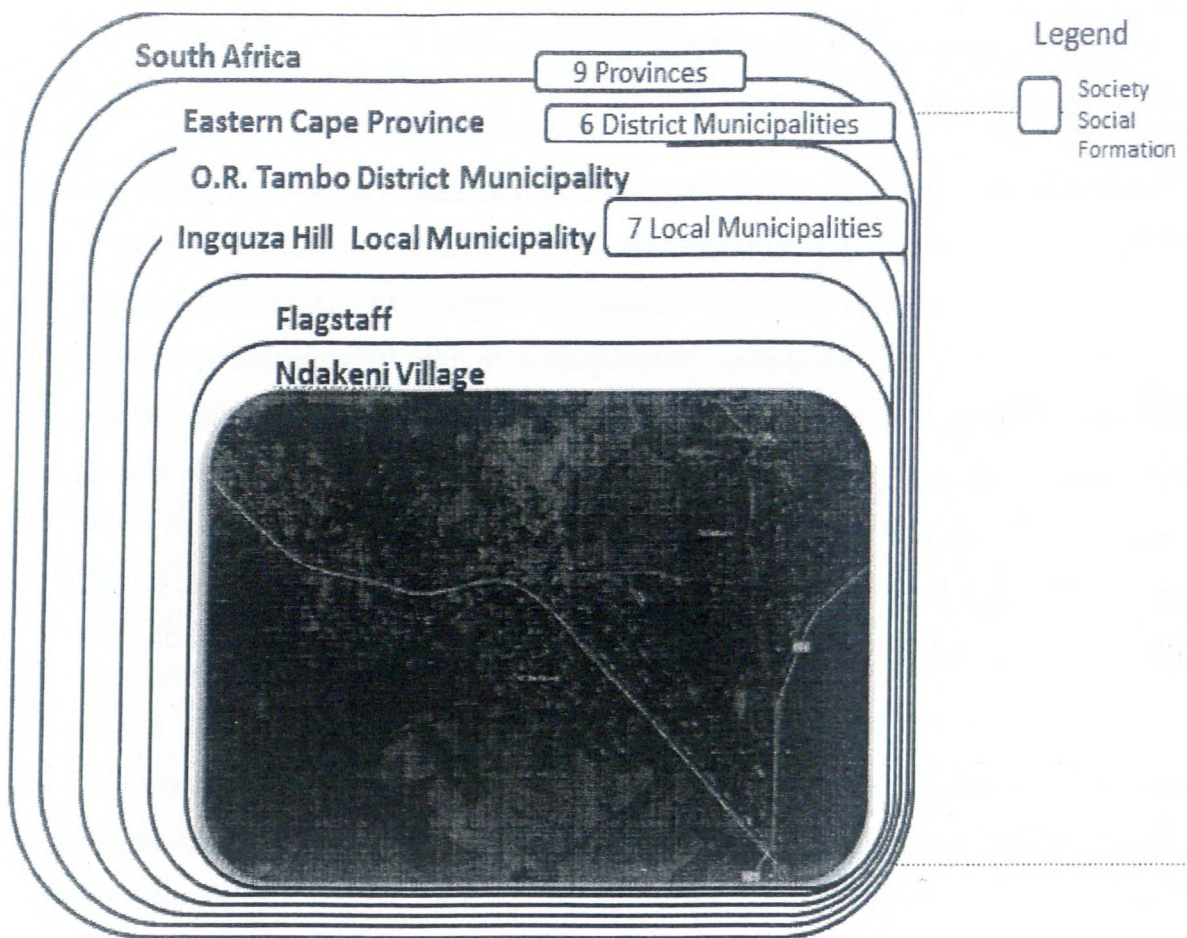
Initially the researcher had planned on interviewing eleven participants (ten caregivers and a coordinator or manager) from each of the three communities that made up part of the research. However caregivers who work outside the centre in Flagstaff area were working in faraway villages and could therefore not be interviewed. The researcher interviewed five participants (four caregivers and one HBHC manager). In Dutywa area the researcher interviewed a total of thirteen participants (Coordinator, Administrator and eleven caregivers). In Stellenbosch eight participants were interviewed. A total of twenty six participants were interviewed and two focus groups (one in Dutywa and one in Stellenbosch) were conducted for the study.

### **4.3. Case 1: Ixabiso Lomntu Community Healthcare Centre**

#### **4.3.1. Background of the community**

The first case was conducted at the Ntlezi Area of Flagstaff, a small town in the north-east of the Eastern Cape Province. The Ntlezi Area is managed by Ixabiso Lomntu Healthcare Centre. The area falls under the Ingquza Hill Local Municipality (IHLM) formerly known as Qaukeni Municipality within OR Tambo District Municipality as shown in Figure 4.1. Ingquza Hill is located at the north west of the OR Tambo District and was formed during the merger of the former “Lusikisiki and Flagstaff Transitional Local Councils and the surrounding rural areas, which were under the “Transitional Representative Councils” (Ingquza Hill Local Municipality, 2011). The seat of the Municipality is in Flagstaff and the municipal area is divided into 27 wards.

Ingquza Hill Local Municipality covers an area of 2476 square kilometres. In 2007 the municipality had a population of 279 795 and 48 701 households (Ingquza Hill Local Municipality, 2011). The municipality is faced with enormous challenges relating to uncompleted work of the infrastructure projects, high poverty rate and inadequate development (Ingquza Hill Local Municipality, 2011). The municipality is poor and it requires “targeted community focused development planning” that deals with poverty and builds a definite base for the creation of a flourishing and sustainable community (Ingquza Hill Local Municipality, 2011). The community is largely rural in nature. Low employment rates and high poverty levels affect the municipality’s ability to generate income from service charges and rates negatively (Ingquza Hill Local Municipality, 2011).



**Figure 4.1: Location of Ixabiso Lomntu Healthcare Centre**

Ixabiso Lomntu Healthcare Centre is a non-profit organisation situated in Ndakeni Location, 25 km North of Flagstaff in Eastern Cape. It operates in Flagstaff and the neighbouring villages under OR Tambo District Municipality. The term “ixabiso lomntu” comes from Xhosa language, which is one of the most spoken languages in Eastern Cape Province, meaning “a person’s worth”. The centre caters for patients who need home-based healthcare services particularly HIV/Aids and TB patients, chronic patients, the elderly, orphans and vulnerable children. The centre has as a four bedroom hospice, a pre-school, a soup kitchen, a place where orphans and vulnerable children live and a garden where they grow vegetables.

The Ixabiso Lomntu Healthcare Centre is currently providing care services to hundreds of people around the Flagstaff area. The centre started operating in 2004 and was motivated by the high rate of HIV infection and the associated stigma around the disease. Twelve volunteers who were trained by Valley Trust saw that many people were suffering and that many of these people did not have any family members to care for them. The stigma around HIV resulted in these patients being treated as outcasts because of the fear of infection. These volunteers approached both the village chief and the members of the community and shared with them the vision they had of opening a hospice where the sick would be cared for. One of the community members decided to open their home to the sick and the NPO started helping many people in Ndakeni, Ncura, Mfundisweni and other nearby villages. Chiefs are part of the traditional leadership in South Africa.

Traditional leadership is “the system of ‘co-operative government’ which was developed in acknowledgement of the diversity of the needs and concerns of the population of South Africa, so the Constitution established the right of communities living under traditional law and custom to influence the way in which the country is run” (SouthAfrica.info, 2010). Eastern Cape, Free State, KwaZulu-Natal, Limpopo Province, Mpumalanga and North West are the six provinces in South Africa that have provincial Houses of Traditional Leaders. “Each provincial House nominates three members to the National House of Traditional Leaders, which elects its own office-bearers.” (SouthAfrica.info, 2010). The National House Traditional Leaders advises the national government on the role of traditional leaders and on customary law. It may also conduct its own investigations and advise the country’s presidency on request (SouthAfrica.info, 2010).

The area is largely rural and is faced with many socio-economic problems such as: high rate of unemployment, lack of education, poverty and poverty-related diseases such as HIV/AIDS, TB and malnutrition. There are many orphans in the community as a result of the high rate of HIV infection. In many households the elderly and the sick are the only adults in the household and the burden of caring for the children fall upon them. This is due to family members migrating to the big cities such as Durban, Johannesburg and Cape Town to seek employment and better living conditions with

the hope to then contribute financially to their families who remain behind in the community.

#### **4.3.2. Results and analysis**

The Ixabiso Lomntu Healthcare Centre is under-resourced and is funded by organisations such as Ikhala Trust, OR Tambo District Municipality, the Department of Social Development and DoH. These funds are however insufficient for the care services required by the community. The centre has 14 caregivers, 6 working at the homes in the surrounding villages and 8 caregivers working at the centre. The centre also has kitchen staff who are responsible for the soup kitchen. The centre usually announces during health campaigns that volunteers are needed in order to find caregivers to address the shortage of caregivers. People who are interested can then approach the centre and receive a basic training which takes roughly a day on how to care for the patients and how to fill in the forms.

##### **4.3.2.1. Who is the caregiver**

To better understand the unit of analysis and the context questions regarding who the caregivers are, their role and the challenges they face were asked. The Table 4.2 provides participants responses regarding the role that caregivers play in HBHC, their experiences and the training they receive. All the participants interviewed in Flagstaff were female. All participants interviewed agreed that caregivers are volunteers and predominately women. The caregivers are responsible for taking care of the sick, elderly, disabled, orphans and vulnerable children in the villages around Flagstaff, Bizana and Ntabankulu.

**Table 4.2: Who is the caregiver?**

	<b>Caregiver Role</b>	<b>No of patient per day/week</b>	<b>Experience</b>	<b>Training</b>
<b>Participant 1</b>	<ul style="list-style-type: none"> <li>• Care for the sick, elderly, orphans and underprivileged people</li> <li>• Health promotion</li> <li>• Help abused/ mistreated elderly</li> <li>• Advise with Social Issues</li> <li>• Treatment support</li> <li>• Door to door visits</li> <li>• Awareness Campaigns</li> <li>• Train family members</li> <li>• Take patients' sputa to the clinic</li> <li>• Check vital signs</li> <li>• Wound care</li> </ul>	<ul style="list-style-type: none"> <li>• 9 + per week</li> </ul>	<ul style="list-style-type: none"> <li>• 6 years (Since 2004)</li> <li>• No previous experience</li> <li>• Grade 12</li> <li>• Motivated by stigma around HIV/AIDS and passion for people and community development</li> </ul>	<ul style="list-style-type: none"> <li>• Before commencing with job at Valley Trust</li> <li>• On-going training on new ways of caring and medications</li> </ul>
<b>Participant 2</b>	<ul style="list-style-type: none"> <li>• Care for the sick, elderly and orphans</li> <li>• Health promotion</li> <li>• Advise on Social Issues</li> </ul>	<ul style="list-style-type: none"> <li>• 3 per day</li> <li>• 12+ per week and emergencies</li> </ul>	<ul style="list-style-type: none"> <li>• 6 years (Since 2004)</li> </ul>	<ul style="list-style-type: none"> <li>• Training at Philani School before commencing with job</li> <li>• On-going training and workshops</li> </ul>
<b>Participant 3</b>	<ul style="list-style-type: none"> <li>• Advise with health Social Issues</li> <li>• Treatment support</li> <li>• Help people in need</li> <li>• Door to door visits</li> </ul>		<ul style="list-style-type: none"> <li>• 6 years (Since 2004)</li> </ul>	
<b>Participant 4</b>	<ul style="list-style-type: none"> <li>• Care for the sick, elderly and orphans</li> <li>• Health promotion</li> <li>• Advise with health Social Issues</li> <li>• Treatment support</li> <li>• Door to door visits</li> <li>• Counselling</li> </ul>	<ul style="list-style-type: none"> <li>• 7 per day</li> </ul>	<ul style="list-style-type: none"> <li>• 6 years (Since 2004)</li> </ul>	
<b>Participant 5</b>	<ul style="list-style-type: none"> <li>• Care for the sick, elderly, disabled, orphans and vulnerable children</li> <li>• Health promotion</li> <li>• Advise with health and social issues</li> <li>• Help at the centre (Hospice, soup kitchen and the garden)</li> <li>• Help vulnerable children and orphans with their homework</li> </ul>	<ul style="list-style-type: none"> <li>• it depends on the caregiver workload</li> <li>• At least 12 per week</li> </ul>	<ul style="list-style-type: none"> <li>• 6 years</li> </ul>	<ul style="list-style-type: none"> <li>• Before commencing with job at Valley Trust</li> <li>• On-going training on new trends in HBHC</li> <li>• Caregivers know their job description and they are thoroughly trained before they work</li> </ul>

The caregivers are called whenever there is a sick person or people who need medical attention. They also act in a supporting capacity to the patients informing the patients about their illnesses, medication, side effects. The caregivers also ensure that the patients take their medication as directed by doctors or nurses and they get all the care they need. All participants agree that care giving is more than just helping with medication, bathing the patient and changing linen- in addition caregivers also help patients with cleaning, cooking, laundry, fetching water from the river or taps, fetching medication, accompanying patients to the clinic, hospital or doctor, take TB patient's sputa to the clinic, gardening, taking care of the children and provide counselling. The caregivers also do door-to-door visits in the villages where they educate people about health issues, help them to apply for IDs, birth certificates and social grants and identify the patients who are in need for home-based care services.

All participants agreed that there are caregivers who work at the Centre and that there are caregivers that are assigned to do home visits in the villages. When caregivers first start working for the Centre they do all the work including working in the kitchen, doing laundry, gardening and taking care of the patients at the centre. By doing a bit of everything a caregivers can come to see where they can contribute the most in the long-term. They also advise the home-based care manager where their passion is. The home-based care manager and other managers then decided where the caregiver must be permanently based. Caregivers who work at the centre work day shift which starts from 06h00 to 12h00 or from 12h00 to 17h30 or the night shift from 17h30 to 6h00.

The caregivers who work at the centre have patients that they care for at home. They visit these patients before they go to work every morning and if the caregiver's shift is too early they start at the centre then do home visits later in the day. Some patients ask caregivers to sleep over in their houses so they can assist them during the night. Caregivers who do home-visits usually work from 7h00 to 16h00 but patients call them anytime when they need assistance even during the night. Responses about the number of patients each caregiver sees per week varied. Three participants said they see at least 12 patients per week while other two said they see 7 and 9 patients respectively.

All participants agreed that they have to see Category 3 patients daily. Some patients are solely dependent on caregivers because they do not have any relatives living with them while others live with their grandchildren. The caregivers need to visit these Category 3 patients early in the morning and spend most of the time with them. They open the windows, empty patients' urine pots and buckets, clean the house, make patients' beds, cook and feed patients, fetch water from the river, do laundry and gardening and all the necessary chores to make the patient comfortable. If a patient does not have food the caregivers inform the centre which then provides the patients with food parcels. The centre also provides patients with transport to and from health facilities when needed. The caregivers at the hospice work shifts during the day and at night.

All the participants who were interviewed started working in 2004 when the Centre opened and none of them had previous experience in care giving prior to joining the Centre. One caregiver mentioned that she completed Grade 12 before working. Two participants stated that the centre was opened because of the high rate of HIV/AIDS and the stigma around the illness.

*I did not have any experience. I just finished my grade 12 and I decided to work as a caregiver and help people in my community. When we started in 2004 the stigma was very high and HIV positive people were treated as outcasts. Their family members were scared of the disease to such an extent that they would not even touch the plates and spoons that the patient was using. They would lock the patient in a room and only open when they give them food. We then saw the need to take care of these people and educate their families about the disease.*

According to participant responses caregivers are trained by different organisations such as Veli Trust, Philani School and the centre before they start working as caregivers and on-going workshops are conducted to ensure that they provide quality care service to the patients. Caregivers are trained by the centre for 5 days before they start working on how to do the work and fill in the care forms. They also attend workshops on VCT, Prevention of mother to child transmission (PMTCT), TB and HIV. Participants 3 and 4 did not provide any information about their training. They are also trained on checking vital signs such as blood pressure and wound care. The centre strives to ensure that there is at least one caregiver in each village, who will identify problems and people in need. In villages where they do not have representation they announce that they need volunteers who are then trained to be caregivers.

#### **4.3.2.1.1. Who is the caregiver: Summary**

- All female, referred to as Onompilo (meaning caregiver or healthcare worker in Xhosa), Caregivers, Community health worker (CHW) or carers.
- A person who cares for the sick, elderly, orphans and vulnerable children and under privileged people in villages around Flagstaff, Bizana and Ntabankulu.
- Caregivers are seen as important people in the area and people come to them with all their health problems.
- Do door-to-door visits to identify patients who need care.
- Act as care/treatment supporter; administer medication, advise patients about their illnesses, medication and side effects.
- Help mistreated or abused elderly, orphans and patients.
- Assist with applying for food parcels and social grants from the Department of Social Development.
- Check vital signs such as blood pressure and wound care.
- Collect sputa from patients' homes and take it to the clinic for TB test.
- Conduct health campaigns and health promotion in the area (including Voluntary Counselling and Testing together with the Nurse).
- Work together with the traditional leaders, local municipality, clinics and DoH and Department of Social Development.
- Give advice on health and social issues.

In summary, a caregiver in this community is a volunteer with basic training who provides a comprehensive service to patients in the community who are totally reliant on such a service.

#### **4.3.2.2. Management of the care service**

Most patients in the Flagstaff community are identified by caregivers and the community. The caregivers meet potential patients when they are doing door-to-door visits. Some are referred to the centre by the nearby clinics. Family members who cannot care for the patients at home bring the patients to the centre and the caregivers care for them at the hospice until their health sufficiently improves for them to leave or until they die. Patients cared for at home do not get discharged especially those who are on chronic medication. The caregivers take care of them and ensure that they continue taking their medication even when they get better, which is especially important for chronic diseases.

The facility works with the traditional leaders in the community such as the chiefs (iiNkosi) and the headmen (ooSibonda nooNozithetyana) who help to ensure the care activities run smoothly. The chief and the headman are important people in the villages and they give permission to the caregivers to visit the people and teach them about health and social issues. During the interviews a participant stated that when one of the patients get seriously ill and they have to call an ambulance to take the patient to the hospital they need to inform the headman or chief. The chief needs to know the situation as he is the leader in the community and can also vouch for the caregiver if something goes wrong. At the centre the caregivers work under the supervision of the home-based care manager.

The home-based care manager the HBHC services and all the caregivers report to her. She develops care plans for patients, updates care plans, checks if the caregivers are doing their job well, does follow-up visits after the caregivers have visited the homes, help them with the problems they face when providing a care service and organising awareness to educate the community about health and social issues. The home-based care manager also works with the professional nurse and caregivers when doing voluntary counselling and testing and health promotion. When the caregivers submit their reports and forms at the end of each week, the

home-based care manager consolidates the information and writes monthly reports intended for the different donors and the and local municipality.

The home-based care manager also plays an active role in recruiting volunteers and training them when they work as caregivers. She has no formal training herself; she learnt how to do the work during the years when she was a caregiver. In turn the manager transfers the knowledge she gained to the new caregivers, she learnt the work during the years when she was a caregiver and she transfers the knowledge to the new caregivers. She is very passionate about helping people in the villages. She stated that their concern is not only for people who are ill or have social problems but for everyone. They do door-to-door visits to all the homes to do talk to the people about health and social issues. They encourage people to live as healthy as possible.

#### **4.3.2.2.1. Management of care service Summary**

- Individuals requiring care services are identified by caregivers in the community through door-to-door visits and awareness campaigns. A small number is referred to the Centre by the nearby clinics.
- The facility works together with the traditional leaders within the community such as the chiefs (iiNkosi) and the headmen (ooSibonda nooNozithetyana).
- HBC manager manages the HBHC program and recruit new caregivers.
- Patients who cannot be cared for by family members at home are referred to the hospice.
- Chronic patients such as HIV positive patients do not get discharged from HBHC, they are cared for until they die.

#### **4.3.2.3. Data elements used in practice**

Caregivers at Ixabiso Lomntu Community Health Centre use two forms that is Patient Record (also known as the O.R. Tambo Reporting format) and Home-based care Statistics forms as shown in Figure 4.2 and Figure 4.3. The centre does not choose the forms they use. They use the forms that are mandated by the different donors. These mandated forms require data that are mostly statistical in nature and relates to about the patients and care services.

**O.R. TAMBO DISTRICT MUNICIPALITY REPORTING FORMAT**

Name of Organisation:

Date:

Date	Scope of Work	Area/Village	Achievements	Challenges	Remarks/ Recommendation	Signature

CHW Name:

Head Man:

Coordinator:

DoH:

**Figure 4.2: Ixabiso Lomntu Patient Record (Adapted from the original form in Appendix C3)**

O.R. Tambo Reporting format is used as a patient record in Ixabiso Lomntu. Each patient has his or her own form which the caregiver fills in during the visit. The form as shown in Figure 4.2 has limited spaces where caregivers can write care details. It has column and rows and few data elements.

**IXABISO LOMNTU COMMUNITY HEALTH CARE CENTRE**

**Moth:** \_\_\_\_\_

**Home Based Care Statistics**

Name of CHW	No of referrals	Total no of patients this month	No of new patients	No of RDV positive	No of deaths this month	No on TB	No on TB/HIV	No of children on ARVs	No of orphans this month

**Figure 4.3: Ixabiso Lomntu Home-Based Care Statistics**

The research participants explained how data elements are presented on the forms, and how they understand and use these elements<sup>1</sup>. Tables 4.3 and 4.4 below shows the data elements that are found on the forms used by caregivers in IxabisoLomntu Community Health Centre when they provide a care service to a patient. The data captured on the paper forms by the caregivers is then used in different reports and to manage the care services.

There are several data elements on the forms, each participant took the researcher through the forms and explained what the data elements mean to them and how they use them. The participant responses are captured in Table 4.3 below.

<sup>1</sup> The different data elements used in three communities and detailed meanings are captured in the disc as Appendix E.

**Table 4.3: Data Elements used in practice**

	<b>Name of the Organisation</b>	<b>Date</b>	<b>Date (Column)</b>	<b>Scope of Work</b>	<b>Area/Village</b>
<b>Participant 1</b>	<ul style="list-style-type: none"> <li>The name of the organisation that provides the care service to the patient</li> </ul>	<ul style="list-style-type: none"> <li>The month and year when care was provided</li> </ul>	<ul style="list-style-type: none"> <li>Date of the visit</li> </ul>	<ul style="list-style-type: none"> <li>What we did at the home</li> <li>The important thing that we do is to teach patients the dangers of not taking the medication, the benefits of taking the treatment correctly, side effects and infection control</li> <li>The work you did at the home e.g. Bathed the bedridden patient or Administered treatment/ medication,</li> </ul>	<ul style="list-style-type: none"> <li>The village where the patient lives</li> </ul>
<b>Participant 2</b>	<ul style="list-style-type: none"> <li>The name of the organisation that provides the care service to the patient</li> </ul>	<ul style="list-style-type: none"> <li>The month and year when care was provided</li> </ul>	<ul style="list-style-type: none"> <li>Date of the home visit</li> </ul>	<ul style="list-style-type: none"> <li>Everything I did at the home e.g. bathe patients, health promotion, change bedding, laundry and prepare food.</li> </ul>	<ul style="list-style-type: none"> <li>The village/area where the patient lives (because we visit patients in different villages)</li> </ul>
<b>Participant 3</b>	<ul style="list-style-type: none"> <li>The name of the patient</li> </ul>			<ul style="list-style-type: none"> <li>The condition and the illness of the patient when you visited e.g. Asthmatic, the patient was alone</li> </ul>	<ul style="list-style-type: none"> <li>The village/area where the patient lives e.g. Ndakeni</li> </ul>
<b>Participant 4</b>	<ul style="list-style-type: none"> <li>The name of the organisation that provides the care service to the patient e.g. Ixabiso Lomntu</li> </ul>	<ul style="list-style-type: none"> <li>Date of the home visit e.g. 3 July 2010</li> </ul>	<ul style="list-style-type: none"> <li>Date of the home visit (the same with the previous date, when you cared for the patient)</li> </ul>	<ul style="list-style-type: none"> <li>What the caregiver did at the home e.g. bath patient, change bedding, wound or sore dressing, mouth care, cleaned, train the family how to care for the patient, administered treatment etc.</li> </ul>	<ul style="list-style-type: none"> <li>The village/area where the patient lives e.g. Ndakeni</li> </ul>
<b>Participant 5</b>	<ul style="list-style-type: none"> <li>The name of the organisation that provides the care service to the patient e.g. Ixabiso Lomntu Healthcare Centre</li> </ul>	<ul style="list-style-type: none"> <li>Date of the reporting format e.g. June 2010</li> </ul>	<ul style="list-style-type: none"> <li>Date of the home visit</li> </ul>		

Most participants stated that the **Name of the organisation** at the top of the patient record (also known as the O.R. reporting format) refers to the name of the centre that provides care service to the patient. There are also two data elements, **date** on the form, one found at the top of the form and the other found on the columns. According to the participants the date at the top refers to the month and year when care was provided and for each month the caregiver has to fill in a separate form. Under each column the caregiver writes the date of the home visit. Only one participant provided (Participant 4) a different response regarding the date at the top, according to her you write the date of the visit for both. Participant 3 did not know how these two data elements are used.

Four participants stated that **scope of work** is all the work the caregiver did at the home. Only one participant had a different response, this participant states that **scope of work** refers to the illness the patient is suffering from, his condition and the state of the home. All participants stated that the **village/area** refers to the place where the patient resides.

The care forms used in Ixabiso Lomntu are inadequate for caregivers to write all the care service details. The spaces under the few data elements on the forms for data input are not enough for more descriptive detailing. Caregivers are required to write detailed reports about the care they provided to the patient. This causes more work for the caregivers and the HBC manager. HBC manager has to condense all the caregiver reports by summarising and aggregating the data from the different forms into one big report at the end of the month.

**Table 4.3.1: Other data elements on the forms used in practice**

Achievements	Challenges	Remarks/ Recommendation	Signatures	Statistics
<p><b>Participant 1</b></p> <ul style="list-style-type: none"> <li>The improvements after I did health promotion (close the toilet seat or washing the hands when coming from the toilet) through observation</li> <li>Patient Progress</li> </ul>	<ul style="list-style-type: none"> <li>Family and patient needs</li> <li>Patient condition worsening</li> </ul>	<ul style="list-style-type: none"> <li>What should be done for the patient e.g. Taking him to a health facility or need treatment support</li> </ul>		<ul style="list-style-type: none"> <li>No of people with different illnesses that I saw e.g. No of TB patients, no of people with MDR and no of new patients</li> <li>All this information is from the patient record</li> <li>Fill it in weekly</li> </ul>
<p><b>Participant 2</b></p> <ul style="list-style-type: none"> <li>The condition of the patient after the treatment (also how they felt)</li> </ul>	<ul style="list-style-type: none"> <li>How you got the patient e.g. I was told by the neighbours, door-to-door, saw the patient outside or met in town.</li> </ul>	<ul style="list-style-type: none"> <li>Patient needs e.g. Treatment or medication, IDs/Birth Certificates or social grants</li> </ul>	<ul style="list-style-type: none"> <li>Patient signature or X if the patient is illiterate or family member of the patient is too sick to sign</li> <li>My signature, coordinator's and the chief's signatures</li> </ul>	<ul style="list-style-type: none"> <li>Things change as we go along with caring</li> <li>Forms change and ways of filling in change</li> <li>The procedure is the same, we write numbers of people we saw</li> <li>We do not include people we did not see e.g. TB patients</li> </ul>
<p><b>Participant 3</b></p> <ul style="list-style-type: none"> <li>The condition and If the patient thanked me after the care service</li> </ul>	<ul style="list-style-type: none"> <li>Patient needs</li> <li>Problems the patient is faced with</li> </ul>	<ul style="list-style-type: none"> <li>I write how I helped the patient</li> <li>I'm not sure how to use this.</li> </ul>		<ul style="list-style-type: none"> <li>My name, total no of patients per month, no of referrals to health facilities and No of patients who need food parcels</li> <li>No of HIV + patients (aka RVD) (these patients need to be tested for TB)</li> <li>No of patients tested for TB (these patients need to be tested for HIV)</li> <li>No of new patients, mostly youth that was living in Durban</li> </ul>

**Table 4.3.2: Other data elements on the forms used in practice (continues)**

	<b>Achievements</b>	<b>Challenges</b>	<b>Remarks/ Recommendation</b>	<b>Signatures</b>	<b>Statistics</b>
<b>Participant 4</b>	<ul style="list-style-type: none"> <li>• Advice you gave to the patient</li> <li>• Referral e.g. ask them to go to the health facility if they don't have money / arrange transport or call an ambulance</li> <li>• Report referrals to the HBHC Centre and the headman</li> <li>• Care Support</li> </ul>	<ul style="list-style-type: none"> <li>• How you got the patient e.g. Home Visit, told by neighbours</li> </ul>	<ul style="list-style-type: none"> <li>• Patient complaints e.g. patient who are tired of filling in the forms for food parcels as they do not get them immediately.</li> </ul>	<ul style="list-style-type: none"> <li>• Signature of family member</li> <li>• Head man signature if there were no family members with the patient</li> </ul>	<ul style="list-style-type: none"> <li>• No of HIV + patients</li> <li>• No of Asthma patients</li> <li>• No of disable patients</li> <li>• No of patients tested for TB</li> <li>• No of orphans</li> <li>• No of referrals</li> <li>• No of patients on ARVs</li> <li>• No of the deceased patients</li> </ul>
<b>Participant 5</b>	<ul style="list-style-type: none"> <li>• Observation</li> <li>• What the caregiver achieved (the patient will tell how they feel after the care service, if you explained what causes the sores the patient might ask to be bathed daily).</li> </ul>	<ul style="list-style-type: none"> <li>• The problems you came across e.g. patient refusing to be bathed. Ask them nicely to at least give them half bath and tell them the benefits of washing daily.</li> </ul>	<ul style="list-style-type: none"> <li>• Things that can help e.g. Gloves, grants, food parcels etc.</li> </ul>	<ul style="list-style-type: none"> <li>• Signatures of the caregiver, headman/ traditional leader, coordinator and municipal officer.</li> </ul>	<ul style="list-style-type: none"> <li>• Total No of patients per month</li> <li>• No of New patients</li> <li>• No of referrals to health facilities</li> <li>• No of HIV + patients with TB</li> <li>• No of the deceased patients</li> <li>• No of patients tested for HIV/AIDS</li> <li>• No of children ON ARVs</li> <li>• No of adults on ARVs</li> </ul>

Although participants gave different responses regarding the above data elements, their responses were converging and coming to the same conclusions (see Table 4.3.1.). They stated that the data element **achievements** refers to what the caregiver achieved during care service such as the improvement in patient condition, improvement after a care service, advice given when certain situations arise, referral and care support. **Challenges** refer to demanding or stimulating situations before they started caring for the patient, during the care service or anything that hinders them from providing quality care service. These challenges may be the worsening of patient condition, lack of resources or poverty or things or things that led the caregiver to the patient.

According to most participants **remarks/recommendation** is whatever they need to inform the care manager about for example patient needs, patient complaints or resources they need during care service. Only one participant (Participant 3) was not sure how this data element is used. Participant 4 could not differentiate between the achievement and remarks/recommendation; she thought the data elements meanings were the same. The data element (**family members**) refers to the signature of the patient, the signature of person that lives with the patient or the neighbour if the patient is too ill. Participants 1 and 3 did not give any responses regarding this.

Then under statistics the participants stated that they write numbers of people they saw, they are grouped according to the illnesses/diseases they suffer from, their age group and their needs.

#### **4.3.2.3.1. Summary Data elements used in practise**

- Caregivers use two paper forms, namely: Patient Record and Tally Sheet. These paper forms have few data elements.
- The data elements on the forms include: name of the organisation, date, scope of work, area/village, achievements, challenges, remarks/recommendation, signature and statistics (number of referrals, total number of patients this month, number of new students, number of RVD visits, number of deaths, number of TB/HIV patients, number of children on ARVs and of orphans).
- The space on the forms is not adequate to write all the details of the care service that was provided by the caregiver. As a result the caregivers are required to write

detailed reports in addition to filling in the Patient Record and Tally Sheet. They take notes at the homes of the patients and write the report when they get to their own homes well after the actual care services were delivered.

#### 4.3.2.4. Caregivers' perception of data elements

Caregivers fill in two forms, one for patient and care details from OR Tambo Municipality and the other one for statistics (From the DoH).

**Table 4.4.: Use of data elements**

	<b>Data Recording</b>	<b>Important Data Elements</b>	<b>Complicated Data Elements</b>
<b>Participant 1</b>	<ul style="list-style-type: none"> <li>• Done at the patients home</li> <li>• Done on book for 1st time visits</li> <li>• Forms (Patient Record and Statistics) and reports</li> </ul>	<ul style="list-style-type: none"> <li>• Patient history</li> <li>• Living conditions</li> <li>• Patient progress</li> <li>• Support Group</li> <li>• Treatment/ Medication</li> <li>• Facility where meds are collected</li> <li>• Clinics visited</li> <li>• Period of Treatment</li> <li>• Patient needs</li> </ul>	<ul style="list-style-type: none"> <li>• None</li> </ul>
<b>Participant 2</b>	<ul style="list-style-type: none"> <li>• Forms (Patient Record and Statistics) and reports</li> </ul>	<ul style="list-style-type: none"> <li>• Patient's Name and Surname</li> <li>• Living conditions</li> <li>• Who they live with</li> <li>• Patient progress</li> <li>• Source of Income</li> <li>• Treatment/ Medication</li> <li>• Facility where meds are collected</li> <li>• Interventions</li> </ul>	<ul style="list-style-type: none"> <li>• None (Coordinator corrects us when we make mistakes and we are trained how to use new forms)</li> </ul>
<b>Participant 3</b>	<ul style="list-style-type: none"> <li>• Forms (Patient Record for each patient and Weekly Statistics) and reports because we do not have enough spaces on the forms.</li> </ul>	<ul style="list-style-type: none"> <li>• Patient needs</li> <li>• Observations (e.g. tongue to see if the patient is eating, swelling, piles etc.)</li> </ul>	<ul style="list-style-type: none"> <li>• Remarks (Not sure what to write here)</li> </ul>
<b>Participant 4</b>	<ul style="list-style-type: none"> <li>• Forms (Patient Record per patient even if they are at the same home, filled in every time I visit the patient and Statistics), notes and reports</li> </ul>	<ul style="list-style-type: none"> <li>• Scope of work</li> <li>• Challenges</li> <li>• Recommendation</li> <li>• Why you need to visit the patient so that you know what to do. It's important to control your sympathy and not cry in front of the family</li> </ul>	<ul style="list-style-type: none"> <li>• None</li> </ul>
<b>Participant 5</b>	<ul style="list-style-type: none"> <li>• Previously wrote reports on a book</li> <li>• Now use Forms (Patient Record and Statistics) provided by our funders and reports</li> <li>• Forms filled in at the home and other details recorded on the book and later on the report</li> </ul>	<ul style="list-style-type: none"> <li>• Treatment</li> <li>• Check patient clinic card</li> <li>• Did TB DOTS</li> </ul>	<ul style="list-style-type: none"> <li>• None</li> </ul>

These forms have data elements and caregivers understand and use these data elements. This section looks at caregivers perceptions of the data elements. Questions regarding data recording, important data elements and complicated data elements on the forms were asked. Table 4.4 shows summaries of participants' responses.

According to the participants caregivers use several ways to record the data during the care service. They fill in forms and also write notes in their notebooks every time they visit a patient. They use these notes to write their full reports towards the end of each month. Participants like the idea of note taking and report writing because it allows them to write details about a patient and the care service provided and add details about the data elements that are not included in the forms. It also allows them to choose data elements that are relevant. They then submit these reports and forms to the home-based care manager who then compiles monthly reports to different donors.

The patient and care details form has different data elements such as date, scope of work, village/area, achievements, challenges and remarks/recommendation mentioned in section 4.3.2.3. During the interviews participants stated that all the forms are useful and the data elements in them are equally important as they portray exactly the care service given to the patient, the challenges they are faced with, the achievements and they can also request supplies needed to make the care service even better or recommend on what can be done to improve their work. All participants stated that Category is one of these important elements. There are three categories: Category 1, Category 2 and Category 3. Category 1 patients are patients who can do almost everything for themselves. They are mostly TB patients who require TB Dots. Category 2 patients are patients that can do some activities on their own but need assistance with others. They are on and off, today they would feel better and walk around and tomorrow they are sleeping. Then Category 3 patients are patients who are fully depended on the caregiver.

Most of the participants do not have problems with filling in the forms because they were trained and the HBHC manger helps them when they make mistakes. Caregivers also record statistics on the provided form which is then sent to the municipality and the Department of Health. The statistics also show the numbers of people taken care of and the illnesses they have .One of the participants stated that following the format on the forms guides them as to which points should be included on the full written report.

#### **4.3.2.4.1. Summary of Caregivers' perception of data elements**

- Data recording done at home of the patient on the forms and notes taken for the Data recording is done at the home of the patient on the designated forms and notes are taken by the caregivers to be used in creating the detailed report
- Detailed reports are necessary because the space on the forms are inadequate to write complex details about the care services provided
- Caregivers like the idea of note taking and report writing because they can add important details about the care service
- For first time home visits data recording is done on the note book
- Caregivers use the forms as a guide on which areas to include in the reports.
- Some data elements are unclear and confusing. On the patient record there are two data elements, date, which are meant to be used differently. One is for the month and year when the care is given and other is the date for each day the care service has been provided to the patient.
- The data elements on the forms are also not enough.
- Other than doing calculations on the tally sheet most caregivers have difficulty with filling in the forms.
- The responses were similar; only one caregiver didn't know how some of the data elements are used.
- Important data elements include *Patient's Name and Surname, Living conditions, Who they live with, Patient progress, Source of Income, Treatment/ Medication, Facility where meds are collected, Interventions, Patient needs, Observations, Scope of work, Challenges and Recommendation.*

In summary caregivers do all data recording at the home of the patient on books for the first visit then later on the forms and also take notes for the detailed report as the data elements on the forms are inadequate. Caregivers also have difficulty with the calculations on the forms.

In summary caregivers do all data recording done at the home of the patient on books for the first visit then later on the forms and also take notes for the detailed report as the data elements on the forms are inadequate. Caregivers also have difficulty with the calculations on the forms.

#### **4.3.2.5. Caregivers' Challenges**

Caregivers are faced with many challenges in HBHC. The challenges are due to the working environment, the work itself, the patients that they care for and also the family members of the patients. Individual participant responses regarding caregiver challenges and other important issues the caregivers need to be aware of when providing a care service are summarised in Table 4.5.

According to the participants the biggest challenge that caregivers are faced with is poverty. People are really struggling in the villages and this makes it difficult for caregivers to do their work as patients cannot take medication on empty stomachs. Often the caregivers have to bring food for the patient from their own homes or ask the neighbours for food until the Centre provides food parcels for them or they get a social grant from Department of Social Development. It is thus a burden on caregivers when they cannot assist patients with these economic challenges. A participant stated

*Our people are poor, they live in poverty. (Looking sad!) You would go and visit the patient at their home and when you get there you would notice that the patient is hungry, he has not eaten the whole day and you cannot give him medication on an empty stomach. So we have to go and ask for food from the neighbours and report the case to the HBHC manager so that the patient can get some food. We sometimes have to bring food for them from our own homes and help them apply for the social grant from the Department of Social Development.*

**Table 4.5: Challenges**

	<b>Challenges</b>	<b>Other important issues</b>
<b>Participant 1</b>	<ul style="list-style-type: none"> <li>• Family providing incorrect information about the patients and living conditions</li> <li>• being accused of meddling in patient's and family issues</li> <li>• Poverty (sad)</li> <li>• Abuse or maltreatment of the elderly and the sick.</li> </ul>	<ul style="list-style-type: none"> <li>• Family History</li> <li>• Patient health, social and living conditions</li> <li>• Severity of the patient's illness and total visiting time (to organise daily route)</li> </ul>
<b>Participant 2</b>	<ul style="list-style-type: none"> <li>• Patients do not welcome us in their homes (sad)</li> </ul>	<ul style="list-style-type: none"> <li>• Approach the Chief or the headman and ask for permission and help</li> <li>• Visit the homes often and develop trust with people</li> </ul>
<b>Participant 3</b>	<ul style="list-style-type: none"> <li>• Patients refuse to give us their clinic cards or give us out-dated ones sad</li> <li>• Unhealthy food OR Lack of food</li> </ul>	<ul style="list-style-type: none"> <li>• Look at all the clinic cards and ensure that they are up-to-date</li> <li>• Observe the patient and the environment</li> <li>• Visit the patients regularly to develop trust</li> <li>• Show them love</li> </ul>
<b>Participant 4</b>	<ul style="list-style-type: none"> <li>• I sometimes feel lazy to bathe the patients</li> <li>• Cleaning patients who have soiled themselves</li> </ul>	<ul style="list-style-type: none"> <li>• Know the number of the patients you see per month and orphans</li> <li>• Show them love and be helpful and they will trust you with their problems</li> </ul>
<b>Participant 5</b>		<ul style="list-style-type: none"> <li>• Ensure that patients take correct treatment/medication</li> </ul>

Other challenges include: patients' refusal to take medication, family members who do not want to take care of the patient when the caregiver cannot visit and people refusing to be helped. All these challenges sadden and emotionally burden the caregivers.

Participants stated that dishonesty among patients and family members is an issue. Patients lie about their illnesses and the medication they are on. When the caregiver

asks to see their patients' clinic cards, (particularly the patients who have been living in another area), they show the caregiver the old clinic cards. They do this for a number of reasons which include being ashamed of the illnesses that they have or not trusting the caregiver to keep the information confidential. Stigma around illness is still a problem in these areas, patients fear others knowing what they are suffering from as they perceive possible becoming social outcasts.

Participants agreed that trust is very important. At first patients are sometimes unwilling to open up to strangers. Family members lie to the caregivers about the living conditions of the patient because they do not want to lose the money they get for the patient's social grant even though they are not helping the patient.

The caregivers can sense when something does not feel right, some patients would cry but be unable to talk to the caregiver about their problems since family members would be present during care. The caregiver would then ask the people to leave so she can discuss issues that are private with the patient. When they are out the patient would open up about the living condition. The patient then speaks to the social worker who addresses these problems. As a result in some cases, caregivers are accused of meddling in patient and family issues.

Participants also mentioned other important things that they look at such as medical history, patient category, patient needs and living conditions. The patient category helps the caregivers organise their day and know which patients to see on a daily basis. One participant stated it is important to know the total number of people she should see per day, week and month.

#### **4.3.2.5.1. Summary of Caregiver Challenges**

- Family members provide incorrect information about the patient and their living conditions in certain conditions. This has a negative effect on caregivers' decision making with regards to the care service and also taints the relationship between the patient and the caregiver.
- In some homes patients are not cared for, the family members take the patients social grant and use it for their own needs. They pretend to care for the patient when the caregivers are around. When the caregivers ask questions they are accused of meddling in family affairs. This taints the relationship between the caregivers and the patients.

- Poverty is also a big problem in the area. Many patients do not work or have a source of income therefore cannot afford to buy food. This is a burden to the caregivers because it becomes their responsibility to ensure there is food at the home of patients as patients cannot take medication on empty stomachs.
- Stigma is also a problem in the community. Patients do not want other people to know what they are suffering from as they fear they will be treated unfairly in the community.
- Sometimes patients and the family members do not welcome caregivers in their homes for numerous previously listed reasons.
- When caregivers start working some patients refuse to give caregivers their clinic cards. Patients do this because they are ashamed of their illnesses, do not want other people to know what they are suffering from due to the stigma around certain illnesses in the area and they do not want caregivers to see that they are not taking the medications.

In summary it can be concluded that caregivers are willing to do far more than what is generally regarded as home-care service and they carry a heavy emotional load about the results of the socio-economic situation at that community

#### **4.3.2.6. Extraordinary Findings**

Caregivers in Flagstaff walk long distances when they visit the patients. They work in the village where they live and in the neighbouring villages. The centre cannot afford to pay some of the caregivers let alone provide them with a transport allowance. There are many people that need care in these villages. The caregivers have to identify these people by doing door-to-door visits and health awareness campaigns. There are few people in these villages that are passionate about care giving and with caregivers being voluntary it results in a situation where few caregivers have to see many patients.

According to the participants who were interviewed there are many reasons why caregivers do the work even though they face numerous challenges. Some care deeply for people in their communities and want to help whenever and wherever they can. Some caregivers who are not getting paid still do the work even when they are not appreciated because they love helping others. Most of the villagers respect and show gratitude towards the caregivers for all the work they do. Villagers see caregivers as leaders and as people they can go to when they have problems.

Caregivers are very close with the villagers and all the families have the caregivers' cell phone numbers and call them whenever there is a sick person any time of the day. They have a good relationship with the traditional leaders such as the headman and the chief, clinics, hospitals, local municipalities and government departments. One participant stated that some caregivers do the work because there is nothing else to do. They want to have a source of income at the end of each month. Others do it because they love caring for the sick, they wanted to be nurses but they could not further their studies so they opted for care giving.

One caregiver mentioned that sometimes she gets lazy to bath the patients and she gets disgusted with patients who soil themselves but she does not show this to them because she does not want to hurt their feelings. She says people have a mentality that caregivers are strong people who do not have any negative feelings but this is not the case, like everyone else they get disgusted or want to sob when a patient is not getting better. Sometimes caregivers feel sad about patients' situations but in front of the patients they need to appear strong and not cry.

All participants stated that they are not allowed to use the knowledge they have outside what they are taught during training. They cannot use home remedies or medicinal herbs on patients unless clear instructions were given to them during workshops. They do not use traditional medicine at all, they use western medicines provided by doctors, hospitals and clinics. They follow the orders even though they know the remedy would help because they do not want to get in trouble with their authorities and in case something happens to the patient.

#### **4.3.2.6.1. Extraordinary findings Summary**

- The centre is under resourced and understaffed. Some caregivers do not get stipends and the centre does not give them transport allowance.
- Caregivers have to take care of a large number of patients in the community. This is because only a small fraction of the people is passionate about caring and wants to be caregivers.
- Caregivers are not always strong as the people seem to think, they also feel sadness and disgust. Like everybody there are things they do not like doing at times they don't feel like doing other activities such as cleaning patients that have soiled themselves.
- Caregivers are not allowed to use their indigenous knowledge such as traditional medicine or medicinal herbs.

It can be concluded that the HBHC facilities have a great lack of funds; they operate under difficult conditions with caregivers caring for many patients without getting a stipend at times.

#### **4.4. Case 2: MIDA Health and Poverty Project**

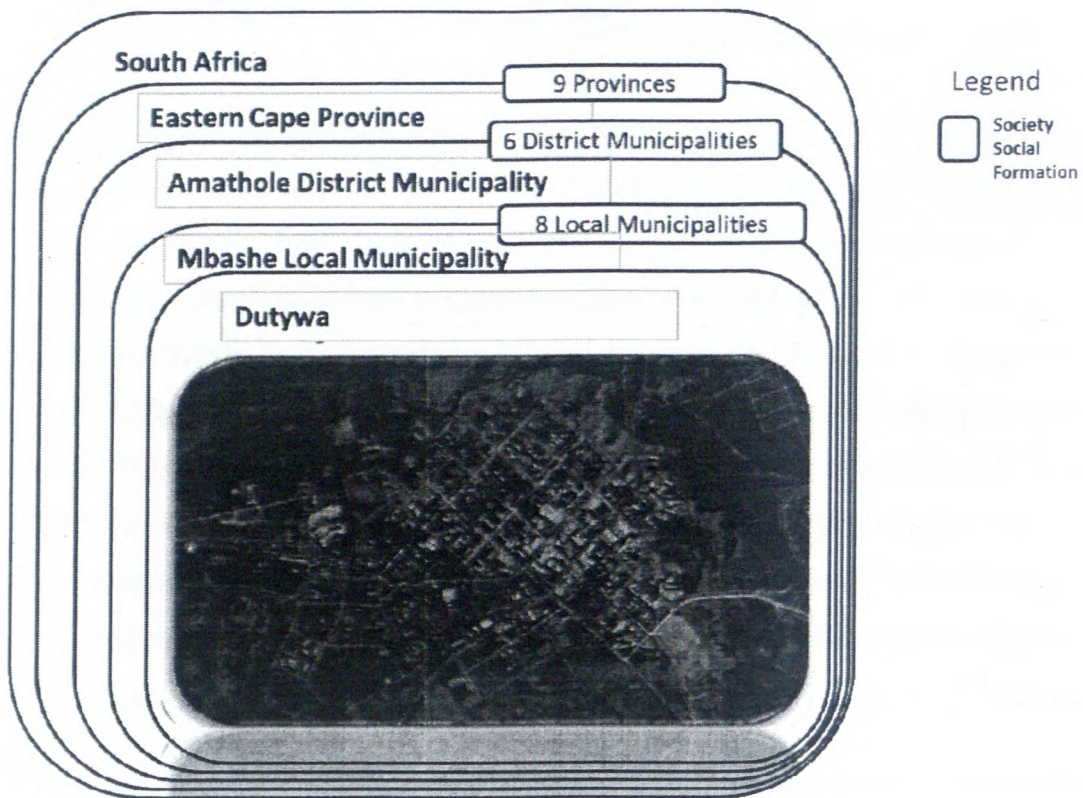
This section discusses and presents the findings of MIDA Health and Poverty Project

##### **4.4.1. Background of the community**

The second case was in the Dutywa region managed by MIDA Health and Poverty Project. Dutywa is a small town located on the eastern part of the Eastern Cape Province. Dutywa was formerly known as Idutywa and was named after a small stream called the Dutywa. Its name was derived from the Xhosa term “ukudutywa” which means ‘being disturbed’ and consequently ‘Place of Disorder’ in a reference to the tribal disturbances that took place there in 1820 (Wild Coast Towns, 2009). Dutywa is under Mbashe local municipality within Amathole district municipality as shown in Figure 2.

MIDA Health and Poverty Health Care is faith based organisation that operates in a small town called Dutywa in Eastern Cape and surrounding areas. It started operating in 1999. The facility is currently involved in a number of activities which include HBHC and poverty eradication projects such as crop and chicken farming. They provide HBHC service to people in Dutywa and neighbouring villages.

The centre provides care mainly to HIV/AIDS patients, orphans and the elderly. The centre is currently servicing 335 patients in 22 villages of Dutywa with the help of 20 caregivers. 10 of these caregivers are paid stipends by the Department of Social Development and the other 10 work as volunteers. These caregivers help patients with cleaning, cooking, laundry, bed baths, fetching water from the river or taps, fetching medication, accompanying patients to the clinic, hospital or doctor, applications for social grants, gardening, taking care of the children and provides counselling. In each village two caregivers are assigned to take care of patients.



**Figure 4.5: Location of MIDA Health and Poverty Project**

#### 4.4.2. Results and Analysis

This section discusses the findings and the analysis of the findings from Dutywa.

##### 4.4.2.1. Who is the caregiver

Caregivers in Dutywa are volunteers that approach the organisation because they are passionate about helping people in their villages. According to the Home-based care manager when the centre started operating some members of the church who love people and taking care of them were approached. When the organisation grew bigger people came and asked to be caregivers.

Currently the organisation does not recruit caregivers, people approach the managers when they want to be volunteers. The organisation uses interviews to see if the potential caregivers are: caring, patient and able to do the work. If they do well during the interview the potential caregivers are then trained on how to do the work and fill in the forms. The centre accepts everybody who has the ability to be a caregiver whether they are educated and have training or not. According to the HBHC manager most caregivers are very good in their work despite the lack of education.

**Table 4.6: Who is the caregiver?**

	<b>Caregiver Role</b>	<b>No of patient per day/week</b>	<b>Experience</b>	<b>Training</b>
<b>Participant 1</b>	<ul style="list-style-type: none"> <li>• Care for the sick and disabled children</li> <li>• Check their living conditions at home (if they are cared for)</li> <li>• Door to door visits to identify people who need care</li> <li>• Awareness campaigns</li> </ul>		<ul style="list-style-type: none"> <li>• 4 years (Since 2007)</li> </ul>	<ul style="list-style-type: none"> <li>• Before commencing with job trained by Kate (MIDA) on caring for HIV+ patients the</li> <li>• On-going training on different illnesses organised by the facility</li> </ul>
<b>Participant 2</b>	<ul style="list-style-type: none"> <li>• The job is hard, goes beyond giving medication and changing linen</li> <li>• Care for the sick (esp. with TB and HIV), disabled children and orphans</li> <li>• Advise with health and Social Issues</li> <li>• Treatment support</li> <li>• Help the sick and disabled children</li> <li>• Door to door visits to identify people who need care</li> </ul>	<ul style="list-style-type: none"> <li>• 6 patients per week, 1 just died (Category 2 &amp; 3 daily and Category 1 once a week)</li> </ul>	<ul style="list-style-type: none"> <li>• 4 years (Since 2007)</li> </ul>	<ul style="list-style-type: none"> <li>• Before commencing training on caring for HIV+ patients</li> <li>• Training on how to fill in the forms</li> </ul>
<b>Participant 3</b>	<ul style="list-style-type: none"> <li>• Care for the sick, defaulters and orphans in villages</li> </ul>	<ul style="list-style-type: none"> <li>• 3 patients per day</li> <li>• 15 per week</li> </ul>	<ul style="list-style-type: none"> <li>• 2 years</li> </ul>	<ul style="list-style-type: none"> <li>• Before commencing trained on how to fill in the forms</li> <li>• Few on-going workshops on different subjects in HBHC</li> </ul>
<b>Participant 4</b>	<ul style="list-style-type: none"> <li>• Care for the sick and hopeless</li> <li>• Give parental care to patients</li> <li>• Advise with health Social Issues</li> <li>• Clean and cook for the patients that live alone and are too ill</li> </ul>	<ul style="list-style-type: none"> <li>• 6 patients per week (Category 2 &amp; 3 daily and Category 1 once a week)</li> </ul>	<ul style="list-style-type: none"> <li>• 1 year</li> </ul>	<ul style="list-style-type: none"> <li>• Before commencing training by Amathole District Municipality</li> <li>• Assessment and Skills Audit and people who passed attended Auxiliary training in East London (including HBHC and 1<sup>ST</sup> AID)</li> </ul>
<b>Participant 5</b>	<ul style="list-style-type: none"> <li>• Care for the sick in their homes</li> <li>• Treatment support</li> <li>• Provide support to the patients</li> <li>• Door to door visits to identify people who need care</li> <li>• Help with house chores</li> </ul>	<ul style="list-style-type: none"> <li>• 3 patients per day</li> <li>• 6 per week</li> </ul>	<ul style="list-style-type: none"> <li>• 2 months</li> <li>• 8 months experience</li> </ul>	<ul style="list-style-type: none"> <li>• Before commencing trained on how to fill in the forms</li> <li>• Few on-going workshops on different subjects in HBHC</li> </ul>
<b>Participant 6</b>	<ul style="list-style-type: none"> <li>• Care for the sick in their homes</li> <li>• Treatment support</li> <li>• Observe the environment</li> </ul>	<ul style="list-style-type: none"> <li>• 5 patients per week</li> </ul>	<ul style="list-style-type: none"> <li>• 1 month, no previous experience</li> </ul>	<ul style="list-style-type: none"> <li>• No training in terms of caring yet (workshops provided from time-to-time)</li> <li>• Trained on how to determine patient category</li> <li>• Relies on other caregivers on how to fill in the forms</li> <li>• Finds awareness campaigns useful to learn about different diseases and illnesses</li> </ul>

**Table 4.6.1: Who is the caregiver? (continues)**

	Caregiver Role	No of patient per day/week	Experience	Training
<b>Participant 7</b>	<ul style="list-style-type: none"> <li>Care for the sick and the elderly at home</li> <li>Treatment support</li> <li>Help with house chores</li> </ul>	<ul style="list-style-type: none"> <li>7 patients per week (1 just died)</li> </ul>	<ul style="list-style-type: none"> <li>9 months (since September 2009)</li> </ul>	<ul style="list-style-type: none"> <li>Before commencing trained on how to fill in the forms</li> <li>Job specification explained by the HBHC manager</li> <li>No other training and workshops yet</li> </ul>
<b>Participant 8</b>	<ul style="list-style-type: none"> <li>As a cg at the Clinic</li> <li>Caring for TB patients</li> <li>Collect patients' sputa</li> <li>TB Dots for TB patients ( also MDR &amp; XDR)</li> </ul>	<ul style="list-style-type: none"> <li>1 patient so far</li> </ul>	<ul style="list-style-type: none"> <li>1<sup>st</sup> month in MIDA</li> <li>3 months experience as a clinic caregiver</li> </ul>	<ul style="list-style-type: none"> <li>Before commencing trained on how to fill in the forms</li> <li>Attended a workshop on HBHC at MIDA</li> </ul>
<b>Participant 9</b>	<ul style="list-style-type: none"> <li>Care for the sick and orphans</li> </ul>	<ul style="list-style-type: none"> <li>18 patients (see cat 3 daily n cat 2 1nce a week)</li> </ul>	<ul style="list-style-type: none"> <li>2 years</li> </ul>	<ul style="list-style-type: none"> <li>Training on caring for TB patients</li> </ul>
<b>Participant 10</b>	<ul style="list-style-type: none"> <li>Door to door visits to identify people who need care</li> <li>Care for the sick esp. those living with school kids</li> <li>Check their living conditions at home (if they are cared for)</li> <li>Help with house chores</li> <li>Awareness campaigns (VCT and health promotion)</li> </ul>	<ul style="list-style-type: none"> <li>10 patients per week</li> </ul>	<ul style="list-style-type: none"> <li>4 years (Since 2007)</li> </ul>	<ul style="list-style-type: none"> <li>Ongoing workshops on different subjects in HBHC</li> </ul>
<b>Participant 11</b>	<ul style="list-style-type: none"> <li>Door to door visits to identify people who need care</li> <li>Care for the sick esp. those living alone or not cared for by family</li> <li>Help with house chores</li> </ul>	<ul style="list-style-type: none"> <li>10 patients per week (4 dependent on me)</li> </ul>	<ul style="list-style-type: none"> <li>1 month</li> <li>previous caregiver experience</li> </ul>	<ul style="list-style-type: none"> <li>Learning from other caregivers how to do the work</li> </ul>
<b>Participant 12</b>	<ul style="list-style-type: none"> <li>Door to door visits to identify people who need HBHC and social care</li> <li>Care for the sick and disabled children</li> <li>Work with the professional nurse and HBHC Manager</li> <li>Awareness campaigns</li> <li>Health promotion with DoH focusing on HIV/AIDS</li> </ul>	<ul style="list-style-type: none"> <li></li> </ul>		<ul style="list-style-type: none"> <li>Before commencing trained on how to do the work and fill in the forms</li> <li>Ongoing workshops on different subjects in HBHC</li> </ul>

The centre currently has twenty caregivers, all female, who undergo continues training and up skilling. Ten of these caregivers are employed and paid monthly stipends by the Municipality and the DoH. It is not easy for caregivers to get stipends and caregivers can spend many years doing the work without getting any stipends. The centre is very transparent about such issues, the HBHC manager tells caregivers from the start that they do not have money and it is possible for the caregivers to work without pay. It is solely the DoH decision when and how many caregivers get stipends. However when the organisation gets other funding they help the caregivers by giving them little money and/or food parcels. Table 4.6 and Table 4.6.1 show summaries of participant responses in Dutywa.

According to 12 participants interviewed in Dutywa area caregivers are people who provide a care service to people such as those that are sick, elderly, disabled children and orphans. The caregivers provide care services to patients in Dutywa and in the surrounding villages. Caregiver duties include door to door visits to identify people who need HBHC and social care, care for the sick (especially those living alone or not cared for by family), the elderly, orphans and disabled children. They also do house chores such as cleaning, cooking and fetching water from the river or nearby water taps. Caregivers also conduct awareness campaigns and health promotion in different villages focusing on HIV/AIDS with DOH. Caregivers work with the professional nurse and HBHC Manager.

Participants stated that honesty and patience are important qualities required in a caregiver. Confidentiality and privacy are also very important. Caregivers need to develop trust with the people they care for. When they visit people's homes for the first time they might not be welcome at the home but caregivers need to be patient so that people can know them and trust them with their problems. Once they develop that trust patients see caregivers as advisors and leaders. One participant stated that

“Some patients treat the caregiver as a parent and they require them to give them some sort of parental care. “

Most caregivers are not well educated and lack formal training in care giving. Some participants stated that they are not educated but they have a passion for helping people in their communities. They are trained before they start working on how to care for the people but usually the training is inadequate, they learn as they do the work. They rely on caregivers who have been working for the organisation for longer and the coordinator to advise and guide them. MIDA Health also hosts workshops where caregivers are trained on different healthcare issues.

#### **4.4.2.1.1. Who is the caregiver: Summary**

- Caregivers are people who provide a care service to people such as the sick, elderly, disabled children and orphans in Dutywa and surrounding villages.
- They do door to door visits to identify people who need HBHC and social care
- They assist with house chores particularly for patients who cannot do anything on their own, live alone or with children who go to school
- They conduct awareness campaigns and health promotion in different villages focusing on HIV/AIDS

- Caregivers are required to be honest and patient
- Confidentiality and privacy are also very important in care giving
- Caregivers need to develop trust with the people they care for.
- Most caregivers are not well educated and lack formal training in care giving but have a passion for helping people in their communities
- Caregivers are trained before they start working on how to care for the people but usually the training is inadequate, they learn as they do the work.
- New caregivers rely on caregivers who have been working for the organisation for longer and the coordinator to advise and guide them.
- Caregivers' ongoing workshops and training on different healthcare issues are provided by the organisation.

Caregivers are people who provide a care service to people who are sick, elderly, disabled children and orphans in Dutywa and surrounding villages. They do door to door visits to identify people who need HBHC and social care, assist with house chores particularly for patients who cannot do anything on their own, live alone or with children who go to school, and conduct awareness campaigns and health promotion in different villages focusing on HIV/AIDS

#### **4.4.2.2. Management of the care service**

The MIDA Health and Poverty Project has partnered with the Department Of Health which pays the stipends of the caregivers. MIDA cannot determine which forms to be used and how they should be used. The forms (and their format) used during the care service is decided by DoH. The centre assists the DoH by collecting the information and populating it on the forms (that is the statistics). The HBHC manager also writes weekly report about the work of the caregivers. Towards the end of the month they take these reports to the DoH.

The centre has its own reports where they identify the different categories of patients that we have. They have categories 1 – 3. According to participants Category 1 patients are the patients who can do most of the things on their own. Category 2 patients are patients who are not totally dependent on the caregiver but can do things on their own from time. Category 3 patients are patients who are bedridden and totally dependent on the caregiver and family members. This helps to know how many patients the centre has in each category.

Caregivers work mostly with categories 2 and 3. Category 1 patients are mostly people who take TB treatment, ARVs and defaulters. Caregivers ensure that the patients take the medication correctly until they finish the course particularly TB patients and refer defaulters to the clinic so that they can continue with the treatment. They also encourage patients on other medications such as ARVs to take their medication correctly. One participant stated that

“We encourage them to take the medication. If they are doing well and they are done with their TB medication we discharge them.”

#### **4.4.2.2.1. Management of care service summary**

- The Centre works in partnership with the Department Of Health which pays the stipends of the caregivers.
- The forms used to capture care details are from the different funders
- The Centre assists the DoH by collecting the information and populating it on the forms (that is statistics).
- The HBHC manager manages the HBHC program
- Caregivers work mostly with categories 2 and 3.

#### **4.4.2.3. Data elements used in practise**

MIDA Health and Poverty Project use six forms which are Patient record, Patient Categorisation Form, Household Registration, NPO Referral and Down Referral, Orphan Identification Form and Tally Sheet.

PATIENT RECORD (Format last updated 31 March 2008)

Patient Information				Information of the NPO		
Name		Religion		Referred from (facility name)*		
Surname		Language		Referred to (NPO name)*		
Gender		Orphan (Y/N)		NPO tel nr		
Age				NPO registration date	Reg Nr	
Home Tel Nr		Cell		Patient Category at registration (1,2 or 3)		
Next of Kin name				Discharge date		
				Discharge type (e.g. recovered, died, transferred)		
CHW name						
Assessment date						
Nursing care plan date						
Date & Time	Category	Care and/or Interventions Provided (Complete while in patient's house)		Carer name & signature	Patient/Family name & signature	

\* Name of facility as in the DHIS

**Figure 4.6: MIDA Health Patient Record (Adapted from the original in Appendix C.1.)**

The patient record shown in Figure 4.6 is used to record patient details, contact details, illness, medication and the details of care service. This form is filled in by caregivers every time they visit the patient to record date, time and details of the care service. The nurse and the coordinator also use this form to check the progress of the patient, monitor the work of the caregivers and update patient care plans.

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**PATIENT CATEGORIZATION ASSESSMENT FORM**

(Format Last Updated: 31 March 2008)

Patient Name \_\_\_\_\_  
 Patient Date of Birth \_\_\_\_\_  
 Patient Register Number \_\_\_\_\_

Please enter the appropriate score for each activity or mental state:

Scores	1	2	3	
DAILY ACTIVITIES	Independent	Needs assistance	Totally Dependent	
Mobility				
Toilet Usage				
Washing				
Mouth Care				
Shaving				
Hair Care				
Eating & Drinking				
Changing of clothes				
Medication				
<b>Daily Activities Totals</b>				= [a]

MENTAL STATE	Good	Fair	Poor	
Orientation				
Memory				
Comprehension				
Emotional Coping Skills				
	None	Some	Constant	
Behavioural problems				
<b>Mental State Totals</b>				= [b]

<b>TOTAL Patient Score [a] + [b]</b>	= [c]
--------------------------------------	-------

PATIENT ASSESSMENT RESULTS			
Patient Score [c]	Patient Category	Category Description	Category Description
< 15	1	Independent	Screen, Train family, Referral to other discipline / Support groups
15 - 25	2	Requires minimum assistance	Moderate HBC needed
> 25	3	Required maximum assistance	Intense HBC needed

Assessor Name and Surname \_\_\_\_\_

Assessor Signature \_\_\_\_\_

Date \_\_\_\_\_

**Figure 4.7: The patient categorisation form**

The patient categorisation form (see Figure 4.7) was introduced by the Department of Health in MIDA Health but none of the participants were using it at the time of interviews. The form is intended to help the caregivers to determine the correct category of the patient.

## HOUSEHOLD REGISTRATION

(Format Last Updated: 31 March 2008)

Physical Address				Registration	
				Date of registration	
				Household register number	
<b>Head of Household</b>					
Name					
Surname					
Gender		Age			
Tel nr home		Cell			
Employer Name					
Employer Address & Telephone					
<b>Other People in Household</b>					
Name	Surname	Gender	Age	Comments (indicate OVC when this person an orphan & register number if the person is a registered patient)	
<b>Environmental &amp; Social aspects</b>				<b>Comments</b>	
Housing	Formal	Informal			
Piped water	Yes	No			
Electricity	Yes	No			
Sanitation (Flush toilet)	Yes	No			
Social Needs	Housing	IDs			
Alternative source of income					
<b>Health Needs</b>		<b>Comments</b>			
Under 5 year health					
Home based care					
VCT					
TB					
Treatment support					
Health Promotion					
Nutrition support					

**Figure 4.8 Household Registration Form (Adapted from the original form in Appendix C.2.)**

Household Registration Form shown in Figure 4.8 is used by caregivers to register homes and details of people who live in the home and those that need care in Dutywa area. The form is filled in when caregivers do door-to-door visits and visit the home for the first time. The home is then allocated a number and the details of the residents are recorded at MIDA Health and Poverty Project.

HOME-BASED CARE (HBC): Tally sheet/ (Month Summary)

(Format Last Update: 31 March 2000)

Province		District	Sub-District												
NPO Name		CHW name/ [Coordinator]	Month & Year												
Data elements		DAY of Monthly (Tally <del>11111</del> / [CHW NAMES])												Total	
Total HBC Visits	Visits under 5 years – total														
	Visits 5 years and older - total														
Type of visits to patients on HBC register	Visits category 1														
	Visits category 2														
	Visits category 3														
Visits palliative care															
Visits Treatment Compliance Support (TCS) TB DOT															
Visits Treatment Compliance Support (TCS) exd TB DOT															
Visits to OVCs															
Visits to patients NOT on HBC register															
Visits to supervised by professional															
Referrals to health facilities	Referred to HF under 5 years														
	Referred to HF under 5 years and older														
Types of referral to health care facilities	Under 5 years rehydrated at home														
	Under 5 years TB contact														
	TB suspect														
	Malnutrition suspect (under/over wight)														
	Defaulter Immunisation and VIT A traced														
	Defaulter TB treatment traced														
	Defaulter mental treatment traced														
Refer to Victim Empowerment Program															
Give birth outside health facility (exd DDA) i.e. home birth															
Male condoms distributed															

Figure 4.9: Tally Sheet (Adapted from the original form in Appendix C.3.)

The Tally Sheet shown in Figure 4.9 is used to summarise the number of people visited by the caregiver each month. The form has two pages and each page is filled in for two weeks. The people are categorised by their illness, patient category and the care they received from caregivers in the end the caregivers write the total numbers for each row.

## ORPHAN IDENTIFICATION

SURNAME	NAME OF ORPHAN	LOCALITY	AGE	SCHOOL	GENDER	GRANT STATUS

**Figure 4.10: Orphan Identification form (Adapted from the original form in Appendix C.4.)**

The orphan identification form is used to capture details of the orphans identified by caregivers in villages around Dutywa. All their details and needs are captured on the form and they are then registered with the centre. A caregiver then is allocated to care for them. Usually the orphans are cared for by the caregiver who identified them unless the caregiver has a big workload. In such cases another caregiver in the same area is given the responsibility to care for the orphan. Some orphans are sick and not well taken care of at home, particularly those who are HIV positive. The family members isolate them because they are afraid to be infected with the disease. The caregivers then educate people about HIV and how it can be transmitted and ensure that the child's wellbeing is considered. They also help to apply for social grants for these orphans, check their clinic cards, ensure that they receive the necessary immunisations, and ensure that they attend school when they are of age.

**Table 4.7.1: Data elements on the forms used in practice**

	<b>Patient Information</b>	<b>Category</b>	<b>Care or Interventions Provided</b>	<b>Defaulter</b>
<b>Participant 1</b>	<ul style="list-style-type: none"> <li>• Patient details e.g. Name, surname, gender, age, religion, address, etc.</li> <li>• Its important to know what the patient believes in e.g. If they are Christian so you can use that to encourage them</li> </ul>	<ul style="list-style-type: none"> <li>• Three categories i.e.               <ul style="list-style-type: none"> <li>- Category 1-: patients who can walk and do things on their own e.g. Patients with HGT that is controllable</li> <li>- Category 2-: patients who can do some things on their own</li> <li>- Category 3-: bedridden patients that cannot do anything on their own.</li> </ul> </li> <li>• Category 3 patients require more care and I start with them daily</li> <li>• Patients are placed in different categories according to how ill there are:-               <ul style="list-style-type: none"> <li>- Category 1-: patient who can walk and do things on their own</li> <li>- Category 2-: patient who is not well but can do some things on their own e.g. A mentally ill patient</li> <li>- Category 3-: bedridden patients that cannot do anything on their own and need assistance with everything.</li> </ul> </li> <li>• The category depends on the condition of the patient.               <ul style="list-style-type: none"> <li>- Category 1-: someone like you and me, they are ill but need assistance with some things</li> <li>- Category 2-: patients that t are on and off, they are feeling better or get worse some days</li> <li>- Category 3-: bedridden patient who need assistance with going to the toilet, bathing or changing the bedding.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Work done at the home e.g. Observe patients and talk to them when taking meds to ensure they do not hide it.</li> <li>• Ask neighbours to help if patient has to take meds twice</li> </ul>	<ul style="list-style-type: none"> <li>• A patient that stops taking meds</li> </ul>
<b>Participant 2</b>	<ul style="list-style-type: none"> <li>• Patient details (e.g. Name, surname, gender, age and contact details), family member, date of care service, and caregiver responsible for the patient.</li> </ul>	<ul style="list-style-type: none"> <li>• Patients are placed in different categories according to how ill there are:-               <ul style="list-style-type: none"> <li>- Category 1-: patient who can walk and do things on their own</li> <li>- Category 2-: patient who is not well but can do some things on their own e.g. A mentally ill patient</li> <li>- Category 3-: bedridden patients that cannot do anything on their own and need assistance with everything.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• All the work I did at the home. It's important to show the total time and details of the care service.</li> <li>• The work done in each home differs according to the patients needs.</li> </ul>	<ul style="list-style-type: none"> <li>•</li> </ul>
<b>Participant 3</b>	<ul style="list-style-type: none"> <li>• Patient details, family members, language, religion and home language</li> </ul>	<ul style="list-style-type: none"> <li>• The category depends on the condition of the patient.               <ul style="list-style-type: none"> <li>- Category 1-: someone like you and me, they are ill but need assistance with some things</li> <li>- Category 2-: patients that t are on and off, they are feeling better or get worse some days</li> <li>- Category 3-: bedridden patient who need assistance with going to the toilet, bathing or changing the bedding.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Work done at the patients' homes e.g. Bed bath, groomed the patient, change bedding etc.</li> <li>• Counselling during VCT campaigns (Testing done by the nurse)</li> </ul>	<ul style="list-style-type: none"> <li>• Children who are not sent to the clinic for their immunisations e.g. Vitamin A</li> <li>• Patients that stop taking their ARTs, TB and mental medications</li> <li>• They are referred to the clinic for a stronger regimen</li> </ul>
<b>Participant 4</b>	<ul style="list-style-type: none"> <li>• Patient Details (name, surname, age, gender), employment status, employer, physical address. and the caregiver responsible for the patient</li> </ul>	<ul style="list-style-type: none"> <li>• The category depends on the condition of the patient.               <ul style="list-style-type: none"> <li>- Category 1-: Patients that are ill but can walk.</li> <li>- Category 2-: patients that are on and off, they are feeling better or get worse some days</li> <li>- Category 3-: bedridden patient who need assistance with everything e.g. going to the toilet, bathing or changing the bedding.</li> </ul> </li> <li>• The category is determined on the first visit</li> </ul>	<ul style="list-style-type: none"> <li>• All the work done the patient's home</li> </ul>	

**Table 4.7.2: Data elements on the forms used in practice (continues)**

	<b>Patient Information</b>	<b>Category</b>	<b>Care or Interventions Provided</b>	<b>Defaulter</b>
<b>Participant 5</b>	<ul style="list-style-type: none"> <li>• Patient Details (name, surname, age, gender), physical address, contact details, religion, home language and the caregiver responsible for the patient.</li> </ul>	<ul style="list-style-type: none"> <li>• Patients are classified into different categories (2 &amp; 3 are the most important)               <ul style="list-style-type: none"> <li>- Category 1-: Patients that are ill but can walk.</li> <li>- Category 2-: patients that can do some things on their own</li> <li>- Category 3-: bedridden patient who need assistance with everything and need to be supervised at all times.</li> </ul> </li> <li>• Patients are classified into different categories (2 &amp; 3 are the most important)               <ul style="list-style-type: none"> <li>- Category 1-: Patients that are ill but can walk.</li> <li>- Category 2-: patients that can do some things on their own</li> <li>- Category 3-: bedridden and seriously ill patients who cannot do anything on their own.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Work done at the patient home and time spent while caring for the patient (Date, time in, time out and total time)</li> <li>• Distribute brochures and condoms and do health promotion</li> <li>• Observe the home and the area where the patient lives</li> <li>• Work done at the home e.g. Feeding the patient</li> </ul>	<ul style="list-style-type: none"> <li>•</li> </ul>
<b>Participant 6</b>	<ul style="list-style-type: none"> <li>• Patient Details (name, surname, age, gender), physical address, contact details, religion, home language and the caregiver responsible for the patient.</li> <li>• Cell no - where the patient can be contacted as there no telephones in rural areas.</li> <li>• <i>First assessment date and nurses visits</i></li> </ul>	<ul style="list-style-type: none"> <li>• Patient category               <ul style="list-style-type: none"> <li>- Category 1-: Patients who can do everything on their own but have a medical condition and takes medication.</li> <li>- Category 2-: patients were seriously ill but got better.</li> <li>- Category 3-: bedridden and seriously ill patients who do not attend any gatherings in the community.</li> </ul> </li> <li>• Patient category according to his/her health               <ul style="list-style-type: none"> <li>- Category 1-: Patients like you and who visit the clinic and take meds until they feel better.</li> <li>- Category 2-: Patients who take special medication and do not stop until instructed by their doctor</li> <li>- Category 3-: very ill patients who need constant observation from the caregiver</li> </ul> </li> <li>• Category 1 – those who have treatments to take but are not so ill AND do not need to be visited daily</li> <li>• Category 2 – those who are on and off (olala evuka) and</li> <li>• Category 3 – bedridden patients (olele paca)</li> </ul>	<ul style="list-style-type: none"> <li>• Details of the care service i.e. Work done at the home, date and time when the work was done and</li> </ul>	<ul style="list-style-type: none"> <li>• People who do not take their medication as directed by the doctor or nurse</li> </ul>
<b>Participant 7</b>	<ul style="list-style-type: none"> <li>• Patient Details (name, surname, age, gender [ubuni]), physical address, contact details, denomination, home language and the caregiver responsible for the patient.</li> <li>• Patient signatures</li> </ul>	<ul style="list-style-type: none"> <li>• Patient category according to his/her health               <ul style="list-style-type: none"> <li>- Category 1-: Patients like you and who visit the clinic and take meds until they feel better.</li> <li>- Category 2-: Patients who take special medication and do not stop until instructed by their doctor</li> <li>- Category 3-: very ill patients who need constant observation from the caregiver</li> </ul> </li> <li>• Category 1 – those who have treatments to take but are not so ill AND do not need to be visited daily</li> <li>• Category 2 – those who are on and off (olala evuka) and</li> <li>• Category 3 – bedridden patients (olele paca)</li> </ul>	<ul style="list-style-type: none"> <li>• Details of the care service i.e. Work done at the home, date and time when the work was done and</li> </ul>	<ul style="list-style-type: none"> <li>•</li> </ul>
<b>Participant 8</b>	<ul style="list-style-type: none"> <li>•</li> </ul>	<ul style="list-style-type: none"> <li>• Patient category according to his/her health               <ul style="list-style-type: none"> <li>- Category 1-: Patients like you and who visit the clinic and take meds until they feel better.</li> <li>- Category 2-: Patients who take special medication and do not stop until instructed by their doctor</li> <li>- Category 3-: very ill patients who need constant observation from the caregiver</li> </ul> </li> <li>• Category 1 – those who have treatments to take but are not so ill AND do not need to be visited daily</li> <li>• Category 2 – those who are on and off (olala evuka) and</li> <li>• Category 3 – bedridden patients (olele paca)</li> </ul>	<ul style="list-style-type: none"> <li>• Details of the care service i.e. Work done at the home, date and time when the work was done and</li> </ul>	<ul style="list-style-type: none"> <li>•</li> </ul>
<b>Participant 9</b>	<ul style="list-style-type: none"> <li>•</li> </ul>	<ul style="list-style-type: none"> <li>• Category 1 – those who have treatments to take but are not so ill AND do not need to be visited daily</li> <li>• Category 2 – those who are on and off (olala evuka) and</li> <li>• Category 3 – bedridden patients (olele paca)</li> </ul>	<ul style="list-style-type: none"> <li>• Patient record acts as a patient card</li> <li>• Details of the patient and the care service</li> </ul>	<ul style="list-style-type: none"> <li>•</li> </ul>

**Table 4.8: Other data elements on the forms used in practice**

Participants responses	Tally Sheet	People in the Household	Environmental and Social Aspects	Health Needs
<ul style="list-style-type: none"> <li>• Province, district, sub-district where the patients live, dates when the care service was provided, Total number of patients visited (under/over 5yrs), age groups, patient categories, type of care they need, care provided, if they are complying with their treatment, are registered with the centre.</li> <li>• Accuracy is important, totals must correspond with the sections filled in</li> <li>• TB and HIV testing, TB DOT, TB or malnutrition suspects or on the Victim Empowerment program.</li> <li>• Also OVCs (People tested for HIV and testing children with HIV+ parents)</li> <li>• It takes to fill each page of the tally</li> <li>• At the end of each week total visits are written</li> <li>• Tally sheet shows how many times each patient was visited</li> <li>• It's important to also show the categories of the patients</li> <li>• suspected for TB</li> <li>• The Tally sheet makes it easier to fill in the forms</li> </ul>	<ul style="list-style-type: none"> <li>• Family members</li> <li>• Names and ages people who live with the patient or the neighbour as a next of kin if the patient lives alone or with children.</li> <li>• Orphans at the home</li> </ul>	<ul style="list-style-type: none"> <li>• Condition of the home or the environment where the patient lives</li> <li>• Environmental issues :- Type of housing, availability of piped water, proper sanitation/flushable toilets &amp; electricity (many homes do not have these)</li> <li>• Social Aspects e.g. Source of income,</li> <li>• Social needs e.g. IDs &amp; social grants</li> <li>• Its important to know these because they show the living conditions of the patients</li> </ul>	<ul style="list-style-type: none"> <li>• If the patient condition is unknown they are referred to the clinic or the nurse who diagnoses and prescribe treatment.</li> <li>• The nurse intervenes when the caregivers are unable to assist the patients</li> <li>• If the patient condition is unknown the nurse tests them for HIV &amp; TB and then refer them to the clinic for medication</li> <li>• People in rural areas do not have money to go to the hospital</li> <li>• Care for children under 5, VCT, treatment support or health promotion.</li> <li>• Care for children under 5 and/or adults, TB DOT</li> <li>• The needs of my adult patients</li> <li>• Health issues e.g. Undernourished child</li> <li>• It is important to know health needs so we know what to do to improve the situation or advise the patients</li> </ul>	

#### **4.4.2.3.1. Summary of data elements used in practice**

- Caregivers in Dutywa use five forms Patient Record, Household Identification form, Orphan Identification form, Tally Sheet and the Patient Categorisation form
- All these forms have many data elements which include patient information (Name, surname, gender, age, religion, address), Category, Health needs, Environmental aspects, People in the household, Care or interventions Provided, Defaulter.
- The caregivers also collect statistics of the patients they visited and these are sent to the DoH.

Some of the data elements found on the forms in Dutywa are patient information (Name, surname, gender, age, religion, address), Category, Health needs, Environmental aspects, People in the household, Care or interventions Provided, Defaulter. Caregivers fill in these forms and collect statistical data.

#### **4.4.2.4. Caregivers' perception of data elements**

Caregivers in Dutywa have difficulty with filling in the forms especially new caregivers. Some data elements are very difficult to work with. Several caregivers stated that it is particularly difficult to determine the patient category and calculate the numbers on the tally sheet. Even though a new form intended to help caregivers in this regard was provided by the DoH, caregivers were not using it and did not know how to use it at the time the interviews were conducted. Also the numbers on the Patient Records and the Tally sheets should correspond. They need to practise to get better at determining the patient category and the total numbers of people seen and their illnesses.

According to one participant it is important to know data elements such as the patient category, household number, environmental factors and the family needs. The patient category helps to determine the route and the care the patients need and how much time is needed to care for them. One participant stated that:

*Patient's medical history is very important in caring and also for reporting purposes. Patient's illness/ disease and the category are also very important because we need to know if the patient is making progress or the condition is worsening. We also use the information to ensure they get adequate care. For example patients that are on category 3 are visited daily.*

Other important data elements are the household number, environmental factors and family needs. According to the participants the household number helps to determine problems of clients in a particular area. The participant stated that

*Environmental factors tell us where the patients get their water, if they have toilets and electricity. We then inform the local municipality, the nurse and environmental affairs department about all the environmental problems such as patients drinking contaminated water from the river due to lack of piped water and toilets. Family needs and caregiver-patient relationship are also important as they have an impact on the health of the patients and the care they receive.*

Some caregivers do not have problems with filling in the household registration and the patient record. Their biggest challenge is with the tally sheet because do not know how calculate the totals and use some data elements. Some caregivers have difficulty in changing the way they fill in the forms especially if they think it is correct. A participant stated:

*I fill I the forms the same way I have been since I started working as a caregiver. It is has not been the incorrect way.*

#### **4.4.2.4.1. Summary of caregivers perception of data elements**

- Caregivers work mostly with categories 2 and 3.
- Caregivers, particularly new caregivers, have difficulty in filling in the forms and using data elements such as patient category and doing calculations on the tally sheets.
- Some data elements are very important, they help the caregivers determine which route to take when visiting patients (that is which patients should be cared for first), how long they should spend with each patient, what their needs are and what their needs are.
- Some caregivers have difficulty in changing the way they fill in the forms especially if they think it is correct.

Data elements such as categories 2 and 3 are very important, they help the caregivers determine which route to take when visiting patients (that is which patients should be cared for first), how long they should spend with each patient, what their needs are and what their needs are. Caregivers also have difficulty in using some data elements.

#### **4.4.2.5. Caregivers' Challenges**

There are many challenges the caregivers are faced with in Dutywa (see Table 4.9.). For some, working in rural areas is a challenge on its own. They have to walk long distances when they go to the patient homes. Many caregivers complain about patients and their family members who do not welcome them at their homes. This makes caregivers sad because their intention is to help the people in need. But they understand that it is not easy for patients to just open up to strangers about their illnesses and problems as there is a problem of stigma. A participant stated that:

*Yo! It's a struggle to work in the rural areas, some people are not very friendly with us, they do not even greet us when we visit and in other homes we are not welcomed at all. Another challenge is that we get to a home and you find that there are family members but they are not very willing to help with the person that is sick and you has a caregiver you have shown them how to give the person a bath and look after them but they are not willing at all.*

There is also stigma associated with caregivers, when patients are seen with the caregivers in the community, some people assume that they have HIV/AIDS and this makes it difficult for people to welcome and open their homes freely to caregivers. It takes patience from caregivers to keep coming even when they are not welcome until the patients see that they are committed and trustworthy. Caregivers have to be patient and visit patients regularly so they can develop the trust.

**Table 4.9: Caregivers' Challenges**

	<b>Challenges</b>	<b>Other important issues</b>
<b>Participant 1</b>	<ul style="list-style-type: none"> <li>• Working in rural areas with difficult and uneducated people "abantu ababomvu"</li> <li>• Unfriendly and unwelcoming people in the villages</li> <li>• Unwilling family members to help in caring for the patients</li> <li>• Patients who do not take their medication properly (they do not swallow the meds)</li> <li>• Stigma by family members towards HIV+ patients</li> </ul>	<ul style="list-style-type: none"> <li>• Monitor patients when they are taking the medication</li> <li>• Educate people about HIV/AIDS</li> </ul>
<b>Participant 2</b>	<ul style="list-style-type: none"> <li>• Patients (esp. TB patients) refuse to take meds</li> <li>• Patients refuse to open up when we visit for the first time or visit with other caregivers</li> </ul>	<ul style="list-style-type: none"> <li>• Trust is vital</li> <li>• Patience</li> </ul>
<b>Participant 3</b>	<ul style="list-style-type: none"> <li>• Disabled children that are not cared for or maltreated at home</li> </ul>	<ul style="list-style-type: none"> <li>• Trust is vital</li> <li>• Encourage people to appreciate and love children despite their disabilities</li> </ul>
<b>Participant 4</b>	<ul style="list-style-type: none"> <li>• It is difficult for people in rural areas to go to the hospital because they do not have money</li> <li>• When people are not sure what they are suffering from they can't go to the hospital to get a diagnosis. They rely on the professional nurse</li> <li>• No equipment to check patient vital signs</li> </ul>	
<b>Participant 5</b>	<ul style="list-style-type: none"> <li>• People who want us to provide medications for them</li> <li>• Unfriendly and unwelcoming people in the villages</li> <li>• Not being seen as real nurses since we do not provide meds</li> <li>• Stigma around illnesses and people being uncomfortable being seen with caregivers</li> </ul>	<ul style="list-style-type: none"> <li>• Patience and trust are vital</li> </ul>
<b>Participant 6</b>	<ul style="list-style-type: none"> <li>• Determining the patient category</li> </ul>	
<b>Participant 7</b>	<ul style="list-style-type: none"> <li>• Difficulty in using the forms</li> </ul>	<ul style="list-style-type: none"> <li>• Some data elements are difficult to understand</li> </ul>
<b>Participant 8</b>	<ul style="list-style-type: none"> <li>• Drinking patients who do not take their medications properly</li> <li>• Patients who refuse care</li> <li>• Patients who think clinics, NGOs and government should provide them with money to buy food</li> <li>• Unsafe routes we have to take when visiting patients</li> </ul>	
<b>Participant 9</b>	<ul style="list-style-type: none"> <li>• Lack of money to buy food and other basic necessities</li> </ul>	
<b>Participant 10</b>	<ul style="list-style-type: none"> <li>• Seriously ill patients that only live with school attending children</li> </ul>	
<b>Participant 11</b>	<ul style="list-style-type: none"> <li>• Lack of training before we start working, we rely on other caregivers to show us what to do</li> </ul>	<ul style="list-style-type: none"> <li>• Training</li> </ul>
<b>Participant 12</b>	<ul style="list-style-type: none"> <li>• Understanding the forms and how they are used (esp. by uneducated caregivers)</li> <li>• Lack of education</li> <li>• No equipment to check patient vital signs</li> </ul>	<ul style="list-style-type: none"> <li>• Caregivers are very good in caring despite their lack of education</li> <li>• Caregivers are not supposed to do all the work at the home, they help and support</li> </ul>

Some caregivers struggle with family members that are not willing to help the patients. They do not feed the patients or change their bedding, they wait for the caregivers to arrive and do everything. This is a problem because most of these patients are bedridden and cannot do anything on their own and the caregiver cannot be there all the time. Another participant stated that they have a problem of patients who refuse to take the medication. Some claim they do not have the correct food they need to take the medication, others simply do not accept their condition and therefore refuse medication. The caregiver explains the importance of taking medication correctly and ensures that they do not default. For those who have defaulted already the caregiver refers them to the clinic and sits with them every day when they take the medication. If the patient has to take the medication more than once a day family members help.

Patients sometimes refuse to take treatment or hide the pills and not take them as directed by the doctor or nurse.

*When I give the patients medication and I would think that the patient has swallowed their pills but sometimes they do not. They hide the pills under the tongue and wait for me to get out. This shows that the patient needs the counselling and to be monitored.*

Another participant stated that when patients seem to be hiding the pills under the tongue she sits, talk to the patient for a long time and make her or him laugh until she is she sure they have swallowed the pills. Another participant stated that there are many reasons why patients refuse to take the medication which include patients who have lost hope and don't think living is an option, others do not realise the importance of taking the medication correctly and others who say the medication makes them sick. Caregivers need to ensure that all these problems are addressed; they teach patients the importance of taking their medication and ensure that they take the medications as directed by the doctor or nurse.

Another challenge for caregivers is that the forms are written in English and they are required to fill them in English. Caregivers are not educated, most of them have only primary school education and they struggle to write details of the care service on the forms. The HBHC manager stated that

*One of the challenges we have is when the caregivers just start working especially the ones who are not that educated, they have difficulty in understanding the forms because they are written in English. They are sometimes very good in caring for the patients despite their lack of education. So we take time to train them in using the forms and calculating the times they spent at the homes until they are comfortable.*

Caregivers also rely on their colleagues to help them with caring and the forms. In Dutywa it is not uncommon to see caregivers working in groups. They are a strong support to the fellow caregivers in the villages as the HBHC manager and the nurse cannot be there for them all the time.

#### **4.4.2.5.1. Summary of caregiver perception of data elements**

- Caregivers work mostly with categories 2 and 3.
- Caregivers, particularly new caregivers, have difficulty in filling in the forms and using data elements such as patient category and doing calculations on the tally sheets.
- Some data elements are very important, they help the caregivers determine which route to take when visiting patients (that is which patients should be cared for first), how long they should spend with each patient, what their needs are and what their needs are.
- Some caregivers have difficulty in changing the way they fill in the forms especially if they think it is correct.

#### **4.4.2.6. Extra Ordinary Findings**

Neighbours as well as family play an important role in caring for the patients in Dutywa. Category 3 patients cannot do anything on their own; they require maximum care and attention. Caregivers cannot be there for them all the time. They rely on family members to assist with caring when they are not around. In cases where patients live alone at the home, their relationship with the neighbours comes in handy, the caregiver asks the neighbours to help the patient with taking the medication and assist with other things at home as caregivers cannot be with the patient all day every day.

Caregivers encourage patients especially those that live alone or with children in their homes to have healthy relationships with their neighbours. In rural areas a family goes beyond the family members, the community is seen as part of this family and people believe in spirit of fellowship, humanity and compassion known as “ubuntu”. This helps the caregiver to be at ease because they know if they ask the neighbours to check on the patient when they are not around they will do it and assist with caring for the patient.

#### **4.4.2.6.1. Summary of extra ordinary findings**

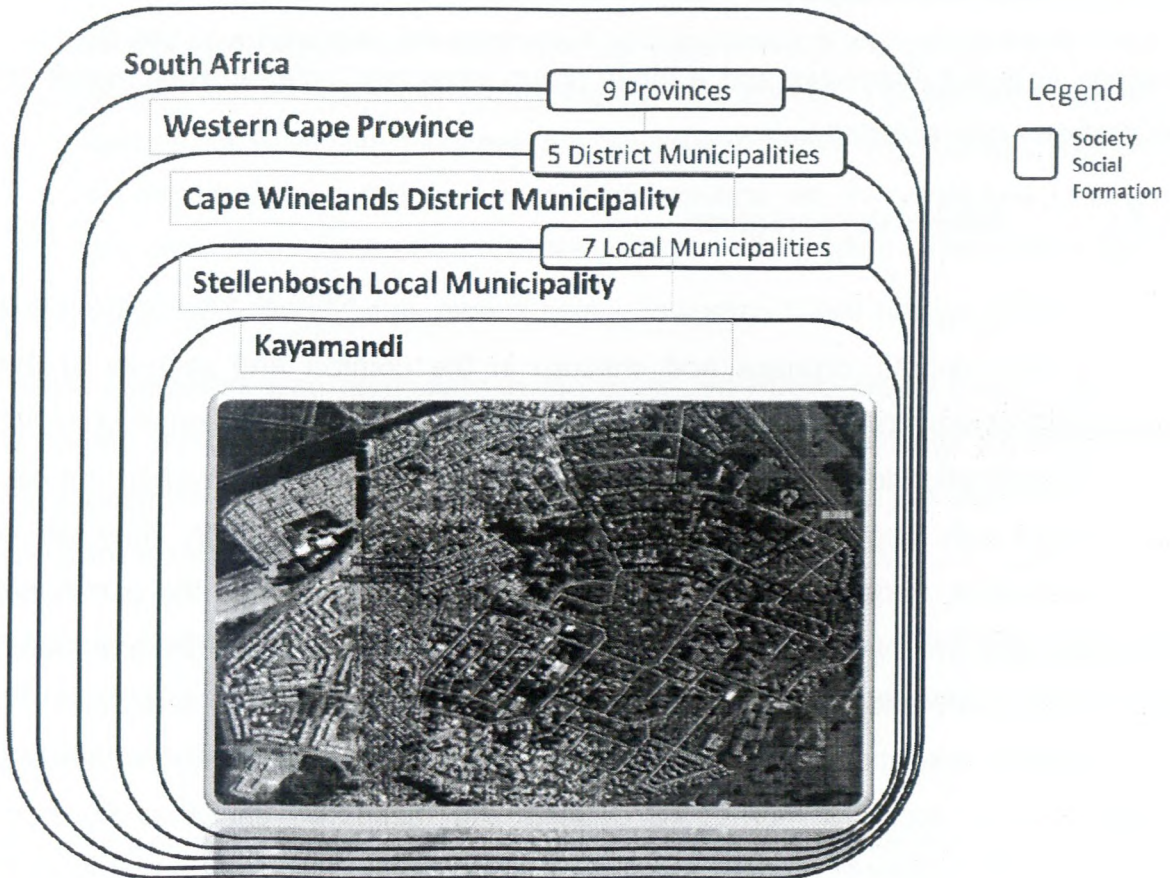
- Neighbours as well as family play an important role in caring for the patients in Dutywa. Caregivers rely on family members and neighbours to assist with caring when they are not around.
- Illiterate or semi illiterate people in Dutywa area are trained and become excellent caregivers

### **4.5. Case 3: Stellenbosch Hospice**

#### **4.5.1. Background of the community**

The third case was conducted in Kayamandi Township in greater Stellenbosch region about 50 km east of Cape Town in Western Cape Province under Wine lands district municipality as shown in Figure 4.11. Kayamandi is a Xhosa term which means “pleasurable home” or “sweet home”. The area is managed by Stellenbosch hospice.

Stellenbosch Hospice, under Hospice Palliative Care Association of South Africa (HPCA), is an organisation that provides a wide range of care services to people in greater Stellenbosch area. The services include home-based care, hospice (In-patient) and psycho-social services. The hospice also provides healthcare services to farm workers and more than 5000 farm workers have benefited. The hospice has more than 70 employees (which include 1 doctor, 9 nursing sisters and 40 carers) and many volunteers (including 3 doctors, spiritual counsellor and a bereavement counsellor).



**Figure 4.11: Location of Kayamandi**

The HBHC facility operates and provides care to more than 888 people in Stellenbosch central and surrounding areas such as Kylemore, Kayamandi, Klappmuts, Cloetesville, P'niel, Ida's Valley, La'nquedoc, Groendal, Franschoek, JonkersHoek, Jamestown and Lynedoch. The HBHC program is managed by an experienced nurse who works with field nurses coordinators and caregivers. For this study the researcher focused on the Kayamandi area where many Xhosa speaking caregivers work and live. People in the area are faced with a number of socio-economic problems such as poverty, HIV/AIDS, lack of education and shortage of jobs and more than 70% live in shacks (Prochorus, 2006). The facility provides care to 202 patients in Kayamandi area.

The HBHC centre works closely with Stellenbosch hospital, local doctors and clinics. Four caregivers work in partnership with the DoH at the clinics in Kayamandi, Cloetesville, Kylemore and Groendal to provide TB supervision.

## **4.5.2. Results and Analysis**

Findings from the interviews and a focus group were conducted in Kayamandi and the analyses are recorded below.

### **4.5.2.1. Who is the caregiver**

All participants agreed that a caregiver – also known as a “carer” – is someone who cares for sick people, orphans and children in the comfort and security of their homes. The caregivers provide palliative care, wound care, chronic care, counselling, fetch the medication for patients or accompany them to the clinic if they do not have people to go with. They bath the patients, do dressings and TB Dots. They also do health promotion, trace defaulters and work with support groups in the community. Caregivers get the names of people who no longer fetch medication (particularly those on TB treatment and ARVs) from the local clinic. They need to do follow-up on these patients, take them to the clinic and ensure that they take the medication as directed by the doctor or nurse. TB patients are monitored until they finish the treatment. If the patients do not have food in their homes or money to buy food the caregivers ask the managers at the Hospice and the Kuyasa Non-Governmental Organisation for food parcels. They also ask for assistance from the soup kitchens in the area.

Grade 12 or Matric certificate and caregiver training are a requirement for caregivers in Stellenbosch Hospice. Only a small number of people who were employed years before this standard was implemented do not have a Grade 12 certificate. When the caregivers get the job with the facility, they work in the in-patient ward and the Hospice where there are trained and assessed on their ability to care for patients for two weeks. When they do well they are then allocated patients in the area where they live and start working. They are trained on how to fill in the forms at the beginning and attend monthly training sessions on counselling, nutrition, TB adherence, childhood illnesses, HIV/AIDS, dementia and depression thereafter. According to caregivers training is very important to better care for the patients. One caregiver stated that:

*We are trained at the beginning and have on-going trainings. You don't just wake up and be a caregiver. We are trained by doing practical work at the wards in the hospice and we are shown everything including how to fill in the forms. It's like being a doctor you don't just heal the sick without any training. With the wounds, we don't just put cotton wool on patients' wounds, we are taught how to clean and dress them. Even with the stroke patients, we are taken to them and shown how to care for them.*

Some caregivers also participate in the Extended Public Works health care training program. All caregivers are taken to the beach in Kleinmond, the mountains at Goedgedacht in Malmesbury on long weekend as part of the 'care for the carer' program to relieve them the pressures of their demanding job.

There are several factors that motivate the caregivers to do the work in Kayamandi area. Most caregivers are often motivated by their passion, and by their revered positions as community carers. One caregiver stated that

*As a student I wanted to be a nurse and help the sick, I understood what the job involves and I knew I wanted to do it despite the challenges. When I could not be a nurse I chose to be a caregiver because I love people and helping in my communities.*

Other caregivers love the challenge the job comes with.

*Being a carer is very hard and challenging. I do it because I love working hard. I cannot give enough love to all my patients but I do it because I love doing things other people cannot do.*

Caregivers from Stellenbosch work from 7h45 to 14h00. They visit up to eight patients per day and they are called whenever patients need them. They are all paid stipends and some of the participants interviewed felt it is too little. One participant stated

*It would be better if they can increase the stipend, it is just too small. It is below R1000.*

#### **4.5.2.1.1. Who is the caregiver: summary**

- Caregiver also known as a “carer” is someone who cares for sick people, orphans and children in the comfort and security of their homes.
- Caregivers provide palliative care, wound care, chronic care, counselling, fetch the medication for patients or accompany them to the clinic if they do not have people to go with.
- Caregivers also do health promotion, trace defaulters and work with support groups in the community.
- Caregivers help struggling patients to request food parcels from the managers at the Hospice and the Kuyasa NGO and soup kitchens in the area.
- Caregivers are required to have Grade 12 or Matric certificate and caregiver training prior working for the hospice and thereafter attend on-going training sessions.
- Some caregivers also participate in the Extended Public Works health care training program.
- All caregivers attend ‘care for carer’ programs to relieve them from the pressures and help them cope with the challenges of the job.
- Most caregivers are often motivated by their passion, and by their revered positions as community carers.
- All caregivers who work for Stellenbosch Hospice are paid stipends.

#### **4.5.2.2. Management of the care service**

Patients are referred to Stellenbosch hospice by local clinics, hospitals and doctors. Due to limited resources the hospice cannot care for everyone in the community. The field nurses from the hospice visit the patient homes to do the initial assessment. The patients are then assigned to a caregiver depending on the area they live. When the patients get better and are able to take care of themselves they are discharged by the hospice.

Caregivers in Kayamandi work closely with the area coordinator. The caregivers and the area coordinator meet every morning to plan the day and to divide amongst themselves the work of caregivers who will not be working on the day. They then walk to their respective areas. The time they spend at each home depends on the needs of the particular patient. They go to different areas of Kayamandi. If there are patients that live alone and are difficult to care for (for example bedridden patients) the caregivers do home visits in pairs but need to fill in separate Caregivers Visit to the home forms and tally sheets. This is rare, most of the time the patients work individually but can walk together to the homes if they work in the same vicinity. At the end of each working day the caregivers meet again with the area coordinator to give a report on what they did at the home, condition of patients and the challenges they were faced with. The area coordinator also checks if they filled in the forms correctly, write the correct patient numbers and categories for caregivers who do not know them. Together with other caregivers they help caregivers who have difficulty in filling in the Tally sheet and do calculations.

The area coordinator is trained and experienced caregiver who provides care service to the patients in their homes and helps to manage the HBHC program in the area. The area coordinator plays a vital role in ensuring that patients get the best care possible. The area coordinator works under the field nurse and the Nursing sister responsible for the HBHC program in Stellenbosch Hospice. The area coordinator also assists caregivers to solve problems they face. The new caregivers are put under her wing for guidance and direction. The coordinator gets up at 5h00 every day and plans the work in her area for the day. She prepares a list of patients to be seen, allocate work of caregivers who are unable to work on the day to other caregivers and herself, give new caregivers a list of the patients to care for.

Caregivers take their patients who can walk to the Hospice or Church in town every Tuesday and this is called Day Care. On this day patients get out of the house to take their minds of the illnesses and problems at home, they talk with many caregivers and other patients, eat, and do activities like colouring and exercise. At the end of the day they are taken home. On Thursdays caregivers visit support groups in their communities where they talk to patients, advise them how to take their medication and check their blood pressure and blood sugar. If the blood pressure is high they refer them to the clinic. The caregivers have a meeting with the area coordinator and the field nurse once a week. On the last day of each month (known as Forum Day) all

the caregivers go to the centre where they meet with the manager to discuss the work they do and the challenges. They are also trained and advised on to do the work better. This day is the day where the caregiver is cared for. They also submit their forms on this day.

#### **4.5.2.2.1. Management of care service summary**

- The hospice caters for people referred to by local clinics, hospitals and doctors.
- The field nurses from the hospice visit the patient homes to do the initial assessment, thereafter a caregiver is assigned to care for the patient.
- Patients who are better are discharged from HBHC
- Caregivers in Kayamandi work closely with the area coordinator who supervises the work in the area. The area coordinator and caregivers meet before and after work to discuss the work.
- Normally caregivers in the area work individually.
- The time spent at each home depends on the needs of the patient.
- A nurse has a meeting with the caregivers in the area at least once a week.
- All forms are submitted towards the end of each month at the hospice. During this time caregivers get a chance to meet and discuss with their colleagues who work in other areas. They are also trained on new things and can discuss problems they encounter when working with the Hospice managers.
- The hospice works in partnership with the DoH and caregivers collect statistics about the patients they care for.

#### **4.5.2.3. Data Elements used in practise**

Caregivers from Stellenbosch Hospice use several forms such as Caregiver Patient Care Record (Home), Record for Home Visits by caregivers, Tally Sheet and Referral forms to capture care details. Data from the forms filled in by caregivers are aggregated and used in monthly reports to different funding organisations. There is Caregiver Patient Care Record (Home) also known as the Home patient record. Each patient has its own form and it has records of the care plan, care plan updates, all the visits by the caregiver and details of the care service. This form is filled in by the caregiver and left at the patient's home under the care of the patient or family member. Nurses, area coordinator and officials from the DoH use this form to check

the quality of care given to the patients and progress. Stellenbosch Hospice is partly funded by the DoH and they require caregivers to work at least 6 hours per day and collect statistics about the patients under their care. They visit the patient's home to check whether the caregivers are providing the care service. The form has different sections which include the Care Plan (See Figure 4.12).

**STELLENBOSCH HOSPICE HOME-BASED CARE**

**CARE PLAN**

**PATIENT:** *Full Name: Wanda box* ID no: *4123* File no: *1234*  
**GENDER:** *male/female* **PHONE:** *021 123 4567* **CAREGIVER:** *Full name*  
**DIAGNO SIS:** \_\_\_\_\_

CARE NEEDS			
Hair wash		Nails	Other:
Full wash		Cathetar care	
Half wash		Foot care	
Mouth/d ental care		Wound care	
Back & Pressure care		Medication family/self	
Nutrition soft/full diet		Nutrition Diabetic, Low salt	
Supply wheelchair		Supply bed accessories	
Monthly BP		Monthly HGT	

PSYCHO-SOCIAL	
Counselling	
Spiritual support	
Socio-economic support	

CARE PLAN UPDATES		
Date	Instructions	Signed

**Figure 4.12: Stellenbosch Hospice Care Plan**

The care plan is filled in by the nurse after the patient has been transferred by the clinic, hospital or doctor to the Hospice. The nursing sister checks the patient condition and determines a better way caring for the patient. When a caregiver has been assigned for the patient, she needs to follow the care plan. The care plan also shows how often the patient needs to be visited. The care plan is then updated according to the progress of the patient.





HOME BASED CARE TALLY SHEET Stellenbosch Hospice Western Cap.



SR: ..... MONTH: ..... AREA: .....

CARER DATA ELEMENTS														PAGE TOTAL	FINAL TOTAL	
DAYS	18	19	20	21	22	23	24	25	26	27	28	29	30	31		
Category 1 visited																
Category 2 visited																
Category 3 visited																
<b>BREAKDOWN</b>																
PALLIATIVE Patients																
CHRONIC Patients																
OTHER children 0-5yrs incl. CIMCI																
OTHER children 6-14yrs																
OTHER adult in home																
ARY Adherence & Support																
TB dots Adherence & Support																
Patients referred from Health facility																
Patients referred to Health facility																
Patients discharged																
Patients transferred																
Support Group attendance																
Patient Care equipment issued to HBC patients																
Bereavement counselling sessions done																
AREA MEETING with caregivers																

Figure 4. 15: Stellenbosch Tally Sheet

Caregivers also fill in the Tally Sheet where all the numbers, categories, illnesses and age groups are shown. Caregivers have to fill in the numbers correctly and these numbers need to correspond with the home visit by caregivers.



2054  
**HOME-BASED CARE REFERRAL**



**Confidential**

<b>REFERRED TO STELLENBOSCH HOSPICE - CHRONIC CARE:</b>			
Category	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
		Hospice File No: <input style="width: 100px;" type="text"/>	
<b>PERSONAL INFORMATION</b>			
CONSENT FOR HBCARE: YES/NO		Date of Birth: ..... Religion: .....	
Name: .....		Language: ..... Sex: <input type="checkbox"/> M <input type="checkbox"/> F	
Address: .....		Next of Kin: ..... Relationship: .....	
Tel No: .....		Address: .....	
Folder No: .....		Tel No: .....	
<b>MEDICAL INFORMATION</b>		<b>DISCHARGE MEDICATION</b>	
Diagnosis: .....		<input style="width: 100%; height: 20px;" type="text"/> <input style="width: 100%; height: 20px;" type="text"/> <input style="width: 100%; height: 20px;" type="text"/>	
Allergies: .....BP: .....Pulse: .....			
Report attached: <input type="checkbox"/> Yes <input type="checkbox"/> No      Discharge Date: .....			
<b>HOME-CARE REQUIREMENTS (tick box)</b>			
Physiotherapy	Developmental Screening	Incontinence care	
Occupational Therapy	Social support	Stoma care	
Speech Therapy	Hospice Care	Tracheotomy care	
Dietician	Frail Care	Postnatal care	
Social Worker	Dressings / Wound Care	Rehabilitation	
Grant	Pressure	Equipment supplies	
Psychiatric follow-up	Nasogastric feeding	Family planning	
Educational needs	Catheter care	Other	
Stock supplied: .....			
Please specify if any of the above are ticked: .....			
Follow-up Date: .....			
REFERRED FROM: .....		NAME: ..... SIGNATURE: .....	
TEL NO: .....		FAX NO: ..... DATE: .....	

**Figure 4. 16: Stellenbosch Home-based Care Referral**

The Home-based Care Referral in Figure 4.15 is used when the chronic patient is referred to Stellenbosch Hospice for home-based healthcare. The category on which the patient is on, the patient needs

N/C

SIGNED: \_\_\_\_\_ DATE: \_\_\_\_\_

**CLIENT ASSESSMENT TOOL**

Activities of Daily Living		Tick			Tick
<b>1. Mobility</b>			<b>8. Dressing</b>		
Moves without help	1		Dresses and undresses without help	1	
Moves with help	2		Dresses and undresses with help/needs reminder	2	
Bedridden, unable to move without help	3		Unable to dress / undress	3	
<b>2. Toileting</b>			<b>9. Medication</b>		
Able to help him/herself	1		Takes medication without help	1	
Needs help	2		Requires help with medication	2	
Unable to help him/herself	3		Unable to take own medication	3	
<b>3. Washing</b>			<b>• Mental Status</b>		
Able to help him/herself	1				
Needs help	2		<b>10. Orientation</b>		
Unable to help him/herself	3		Knows time, place and people	1	
<b>4. Mouth Care</b>			Needs help	2	
Able to help him/herself	1		Unable to tell date, time or place	3	
Needs help	2		<b>11. Memory</b>		
Unable to help him/herself	3		Memory good / no help needed	1	
<b>5. Shaving</b>			Needs help	2	
Able to help him/herself	1		Unable to tell date, time or place	3	
Needs help	2		<b>12. Ability to understand instruction / comprehension</b>		
Unable to help him/herself	3		Able to understand when asked to do something	1	
<b>6. Hair Care</b>			Needs help to understand / comprehend	2	
Able to help him/herself	1		Unable to understand	3	
Needs help	2		<b>13. Coping Skills</b>		
Unable to help him/herself	3		Able to cope with their emotions	1	
<b>7. Eating &amp; drinking capabilities</b>			Requires help coping with emotions	2	
Able to help him/herself	1		Unable to cope with emotions	3	
Requires help	2		<b>14. Behaviour</b>		
Unable to eat or drink	3		No difficult behaviour	1	
			Sometimes behavioural problems	2	
			Constant difficult behaviour	3	
<b>Score</b>	<b>Category</b>	<b>Category Description</b>	<b>Home-Based Package</b>		<b>TOTAL</b>
14	1	Independent	Screen; Train family; Referral to other disciplines / Support groups		
15-28	2	Require minimum assistance	Moderate HBC needed		
29-42	3	Require maximum assistance	Intense HBC needed		

**Figure 4. 16: Stellenbosch Client Assessment Tool**

Stellenbosch Client Assessment Tool in the figure above (Figure 4.16) is used to assess the condition of the patient, things the patient can do without assistance and to determine the category. This form is used when the patient is referred to the hospice for the first time. This is essential when the patient is first admitted by the facility for care to determine the type of care the patient requires and allocate a caregiver. The form is filled in by the field nurse at the beginning of care and is also updated as the patient condition changes. It is part of the home patient record that is left at the home. The caregivers can see things the patient can and cannot do on their own.

#### **4.5.2.3.1. Summary data elements used in practice**

- Caregivers use several forms such as Caregiver Patient Care Record (Home), Record for Home Visits by caregivers, Tally Sheet and Referral forms to capture care details. Data from the forms filled in by caregivers are aggregated and used in monthly reports to different funding organisations.
- Each patient has its own Caregiver Patient Care Record (Home) (also known as the Home patient record) that has records of the care plan, care plan updates, all the visits by the caregiver and details of the care service.

#### **4.5.2.4. Caregivers' perception of data elements**

In Kayamandi area caregivers use many forms when they provide a care service. Most of them are very confident in using most of the data elements because they have been working for the hospice for many years. However those who have just started have difficulties. They do not know how some of the data elements are used because they have not used them yet even though they were shown how to use the forms before they started working. Some caregivers have used some data elements (such as other children 6-14) years but they are not sure what exactly is required of them. A participant stated that:

*I am not clear as to what I am supposed to write under 'Other children 6-14 years'. I started working here last year and I understand some of the things well. I am aware that we need to talk to them and ask about school and other things but I still have difficulty with this.*

Some stated that the forms used at the hospice during the training are not the same as those used at the homes and the forms change all the time. Calculating totals and filling the tally sheet is a problem for both experienced and new caregivers. Most caregivers have difficulty calculating the start time, end time and total time spent at the home because of the work they do. They sometime end up spending more time than in intended attending to the patient and family members and when they have to fill in the forms they cannot calculate the amount of time spent. They make many mistakes and the forms become untidy as they keep scratching. They also have difficulty in doing tally sheets as they contain total numbers of patients seen, their categories and illnesses they suffer from and the care they got. One caregiver stated

it is extremely difficult to fill in the tally sheet, she sometimes write on wrong columns and write two categories for one patient and this causes problems.

The area coordinator suggested that caregivers write the totals and fill in the tally sheet with a pencil. Some caregivers particularly the new ones leave the totals blank because they cannot do it on their own. When the caregivers meet at the end of the day the area coordinator and the other experienced caregivers check if the totals are correct and the tally sheet is filled in correctly and help those who cannot calculate the totals on their own. Then they erase and write the totals using a red pen. According to the participants, the tally sheet is very important; it shows the number of patients visited and helps caregivers keep track of the work done without reading the detailed home visit forms. The numbers on the Tally Sheet and Caregiver home visit forms should correspond.

The participants stated that one of the important data elements they deal with is the patient category. The patient category causes a lot of problems when it is not used properly. Caregivers need to know the patient category to determine the route to take, the care they should provide and the total time they need to spend with the patient. For example, if the patient category is category three, it means the patient is dependent on the caregiver and requires maximal care. The caregiver needs to see such patients first every day and spend more time in their homes. If caregivers put the patient on a wrong category this will affect the type and quality of care the patient receives. For that reason caregivers rely on field nurses to determine the category of the patient when the patient had been referred to the hospice and to update the category. Thereafter the caregivers will just copy the category written by the nurses on the home patient record or get the categories from the coordinator who has a list of all patients in the area and their categories.

Some caregivers stated that they also know the category of the patient by looking at the number of digits of the patient number. According to them if the patient number has 3 digits then the patient is category 1 and if patient number has 4 digits then the patient is the category 4. One caregiver said she thinks that the **category** works the same way with **stages of illnesses** such stages 1, 2 and 3. Other caregivers stated that if the patient is category 3 they are on palliative care and TB treatment or on ARVs. Most Category 1 patients are those on chronic medication such as diabetic and when they suffer from hypertension. This way of looking at the number of the

digits on the patient number is not accurate, it eliminates category 2. Caregivers do not know which patients are in category 2. This leads to them marking incorrect categories and/or marking the same patient twice with different categories on the tally sheets. One participant stated that when she does not know the category of the patient and the condition she leaves it blank so that the area coordinator can fill it in. This is a problem because if the caregiver does not know the condition of the patient, the patient category and the patient number they said they use to determine the category then it is very likely that the patient will not get the right care.

Understanding English is very important for caregivers in Kayamandi as the forms are written in English. They also get pamphlets about different issues written in English, they need to explain these to their patients who cannot read English. Reading is not a problem for most new caregivers as they all have passed Grade 12. However this is not the case for old caregivers. Participants stated that the language is sometimes is a problem, they are required to fill in the forms in English and some caregivers cannot express themselves well in English even though they have Grade 12 Certificates. This leads to missing care details as caregivers do not know how to write them in English. Stellenbosch Hospice has forms written in Afrikaans but not in Xhosa and they cannot write care details in Xhosa as the Hospice does not have resources for translation. Some caregivers do not know what data elements such as medication delivered and area meeting mean even though the nursing sister delivers medication to the patients and has weekly meetings with them. This is clearly a language problem.

Caregivers are allowed to use their knowledge and judgement when caring for the patients. This helps because caregivers work in resource-limited settings. One caregiver stated that if they do not have enough buchu water to clean the patients' wound she uses boiled water and salt. A new caregiver who had just started working at the community stated that she is not aware whether caregivers are allowed to use their own knowledge but personally she would, particularly when she runs out of medications.

*Personally I would use my own knowledge for example if I have patients that are coughing or have diarrhoea and I don't have the meds to give them I would prepare some home remedies using honey to relieve cough. For a child that has diarrhoea I can mix warm water with 8 teaspoon of sugar and a half a spoon of salt to give them quick relief. The hospice does not have problem with this knowledge as it is general knowledge.*

Some participants stated that they are only allowed to use home remedies on the brochures they get from the hospice. If they think something else will work such using warm water and salt to clean wounds or anti-bacteria known as “uzifonke” they need to obtain permission before they use it on patients. They do not use other traditional medicines such as African Wormwood known as “umhlonyane” in Xhosa or sprig also known as “iboza” even if they know it helps with the cough or flu because they do not want to get in trouble with the authorities. They use home remedies such as lemon and warm water.

#### **4.5.2.4.1. Summary of Caregivers' perception of data elements**

- Most caregivers in Kayamandi are confident in using the forms because they have been working for the hospice for many years.
- The main problem that both experienced and new caregivers have with the forms is with the patient category and the calculations on the Caregiver Home visit record and the tally sheet.
- New caregivers experience many problems with the forms; they depend on their colleagues and the area coordinator to assist them in filling the forms until they can complete it on their own.
- Caregivers feel some data elements (such as the patient category) are very important and can cause a lot of problems if not used properly.
- Caregivers have come up with ways to determine which category the patient is on by looking at digits of the patient number. However there are problems related to this way.
- Nurses determine and update the patient category and caregivers use the given category on the forms.
- Understanding is a requirement in Stellenbosch as caregivers need to translate the information written on pamphlets to non-English speaking patients and their families.

- Caregivers are not well educated and therefore have a problem with writing care details on the forms as they cannot express themselves well in English.
- Caregivers are allowed to use their indigenous knowledge, experiences and judgment in caring for the patients as long as it does not affect the patient negatively.
- Caregivers are allowed to use only home remedies on the pamphlets they get from the centre and 'western' medicines not traditional medicines or herbs even though they know these can help

#### **4.5.2.5. Caregivers' Challenges**

During the focus group and interviews participants stated that most people in the area live in shacks, caregivers and nurses have to visit the patients in these shacks and see the difficult condition the people live in. The township is unsafe and caregivers are scared of being robbed and their possessions being taken by naughty boys. The caregivers have to walk long distances in bad weather conditions when visiting the patients' homes. The DoH funds part of the caregivers' stipends therefore expects them to work at least 5 hours per day regardless of the weather.

Some patients refuse to allow caregivers to work and care for them and caregivers have to respect that. Patients who want the assistance from caregivers sign consent forms when the caregivers visit for the first time to show that they do not have a problem working with them and other care workers. When it rains some patients do not open for the caregivers, they chase them away and the caregivers have to leave after walking long distances to see the patients. Some patients do not want the caregivers to visit often because of the stigma.

Caregivers have to fill in many forms, this is difficult and time consuming. They cannot fill in all the forms at the home because they need to focus on the patient so they do the remaining forms at the end of the week. They also have difficulty with filling in these forms because they do not have stationery. Often the data captured is inaccurate, incomplete and gets lost because of these challenges.

#### **4.5.2.5.1. Summary of caregivers' challenges**

- The areas where the caregivers work are in bad conditions and unsafe.
- Caregivers have to walk long distances when visiting the patients.
- People in the community are sometimes not very welcoming and they refuse care.
- Stigma is still a big problem in the Kayamandi area; as a result some people do not want to be seen with caregivers.
- Caregivers have to fill in many forms and do many calculations. This is time-consuming, gets frustrating at times and it takes away caregivers' attention from the patients.
- The money that caregivers get is very little.

#### **4.5.2.6. Extra Ordinary Findings**

One participant stated that she has difficulty doing observation such as checking the skin of the patient or assessing the condition of the patient to see whether the patient is getting better or worse. This becomes a problem because the caregiver cannot suggest improvement to the care. The nurse and the area coordinator have to intervene to ensure proper observations are done and the patient gets the best care possible.

To address issues of confidentiality and privacy in case of loss of care forms, the caregivers do not write the full names of the patient, they write the patient number, the full names are only on the home patient record which the patient keeps in her home. If the lost forms are found by the people in the community, they will not know who the patient is because only the patient number is written even if they know the home address.

##### **4.5.2.6.1. Summary of extra ordinary findings**

- Some caregivers have problems with doing some of the activities such as observations
- Caregivers do not write the patient name and surname on their home visit forms and tally sheets to ensure privacy and confidentiality in case the forms get lost. They only use the patient number.

#### **4.6. Conclusion / Summary of the cases**

There are many similarities and differences in the way the HBHC program is carried out in all three areas. In all three cases the choice and use of forms is largely influenced by the funders. Stellenbosch Hospice has more resources and the HBHC program runs smoother than in the Eastern Cape Province. All three cases work together with government departments, such as DoH and DSD, and many other partners. Both provinces do amazing work and there are many people who are passionate about caring and making a difference in the lives of people in their communities. HBHC centres in both provinces work hand in hand with people in the communities. However in both provinces caregivers are faced with enormous challenges with the work itself and using the different forms during care service provision.

There are also some similarities and differences in the way caregivers use and understand the data elements. These patterns will be discussed in detail in the discussion chapter (Chapter 5).

## **CHAPTER FIVE**

### **5. Discussion**

The chapter discusses the findings in Chapter 4 and how they relate to the literature. The chapter also checks if the research question and sub questions were answered. CoP, community learning, socio-technical theory and social representations are used as lenses to look at the data.

#### **5.1. Introduction**

During the presentation and defence of the research proposal the study had the main research questions and four sub questions as shown in Table 5.1. However as the researcher started writing more questions were added on the study to better explain the interaction of caregivers from different areas with data elements and the role the indigenous knowledge plays on it.

The main question that this study considers is: **What happens when caregivers from various communities interact with data elements when providing a care service?**

The sub questions are:

- Which data elements are relevant to HBHC, and caregivers in particular?
- How are data elements presented on different forms and reports in HBHC?
- What is the significance of indigenous knowledge regarding the use of data elements?
- How may indigenous knowledge be better utilised (e.g. captured) in terms of more effective data element usage?
- How are data elements used differently in different communities?
- How are data elements used differently/similarly in different communities?
- Which differences occur in terms of indigenous knowledge uses?

**Table 5.1: Research question and sub questions in the research proposal**

<b>Research Question</b>	What happens when caregivers from various communities interact with data elements when providing a care service?	
<b>Sub questions</b>	<b>Research method(s)</b>	<b>Objectives</b>
1. Which data elements are relevant to HBHC, and to caregivers in particular?	Literature review , initial observations in CPUT project, interviews, focus groups and participant observation	Describe the use and presentation of data elements in three HBHC providers  Identify or define an initial set of data elements for HBHC
2. How are data elements presented on different forms and reports in HBHC?	Initial observations, document analysis, interviews, focus groups and participant observation	Describe the use and presentation of data elements in three HBHC providers  Identify or define a core set of data elements for HBHC from the care forms
3. How is (indigenous) knowledge regarding how caregivers use data elements captured and understood?	Interviews, focus groups and participant observation	Harness caregivers' indigenous knowledge of their interactions with data elements  Analyse the captured indigenous knowledge to identify patterns of use
4. How are data elements used differently in different communities?	Initial observations, Interviews, focus groups and participant observation	Describe the differences in the use of data elements in differing HBHC contexts  Identify or define a core set of data elements for HBHC based on the care service provision in different communities.

This chapter is grouped using the different sub questions asked in this research, the findings are then analysed and how the questions were answered.

## 5.2. Caregiver Profile

During the data collection process, questions around the caregivers' skills, education level, experience, training, recruitment, environment they work in, motivators and remuneration were asked. It is important to understand who the caregivers are, the work they do and the environments where they work before looking at their use of data as these have an effect on how caregivers understand, use and interpret data elements in their daily activities. This provides for the context in which the home-based healthcare services are provided.

Four caregiver profiles were identified in this study. These profiles are literate and experienced, literate and inexperienced, illiterate and experienced as well as illiterate and inexperienced.

- Literate and experienced caregivers are caregivers who have finished Grade 12, can read and write English without any difficulty and have been working in HBHC for many years. They do not experience many problems with caring for the patients, they know the job fairly well and act as mentors and guides to new caregivers.
- Literate and inexperienced caregivers are caregivers who have passed Grade 12 but have little or no experience. These caregivers include the caregivers who have just started working in HBHC. Most of the caregivers in this profile are very young, they opted for care giving because they could not study further and some have always wanted to be nurses and care for the sick but they did not have funds to study for nursing.
- Illiterate and inexperienced caregivers are caregivers who have little or no experience and little or no education. They are still struggling with caring for the patients because they have just started working as caregivers and they have difficulty with English. These people are not very common in Kayamandi as Grade 12 certificate and some form of training are prerequisite for being a caregiver. However in Eastern Cape it is very common as HBHC centres take anyone who willing and has a potential to be a good caregiver regardless of education, experience and training.

- Illiterate and experienced caregivers are caregivers who are very good in care giving but are not educated. These are mostly older women who love people and caring for them but struggle in reading, writing and speaking English.

In all three cases caregivers interviewed were female. A large majority of home-based caregivers in South Africa are women (Peacock & Weston 2008). Also in Xhosa communities women are generally seen as carers. Most women at homes assume the role of being the family caregiver to their loved ones when they are not getting care services from the NGOs and caregivers that work for them. In cases where there are no older women, girls take this responsibility of caring for their family members, particularly older members and younger siblings.

Caregivers are one of the most important groups of people in HBHC because they provide the HBHC service to patients. Caregivers from both provinces work in extremely difficult conditions and they walk long distances in bad weather. In Flagstaff and Dutywa areas caregivers help to identify patients who need HBHC services and do health promotion by doing door-to-door visits to the homes in the villages. They also do awareness campaigns in halls, churches, schools and the headman's home to educate people about health and social issues. Most HBHC have only one nurse working in all areas. In Dutywa the nurse can visit patients once in a while and caregivers ensure all is well with the patient in the meantime.

### **5.3. Challenges**

Caregivers are faced with a number of challenges when they do their work. During interviews with caregivers in Eastern Cape Province, many caregivers felt that one of the biggest challenges they face is when they visit the homes for the first time to identify patients who need a care service, the patients usually do not welcome them in their homes as they feel they cannot talk to strangers about personal things such as health and social problems. The case is the same in Western Cape Province; patients are not always welcoming in their homes. The caregivers need to be very patient and continue visiting the patients even they do not want to talk to them until they earn their trust. For some caregiver, particularly new ones this is very difficult because they expect the patients to be the ones begging the caregivers to help them.

Another challenge is patients or their family members who provide false information about their living conditions, patient's health status and medical history. They feel this is a problem because they do not know the exact status of the patient, the medication that they need, illnesses they are suffering from. It also affects the decisions they make and hinders smooth care service delivery. Moreover the family members tend to hide the patients living conditions because they are afraid to be reported to the Social Development Department for misusing the patient's social grant. Family members usually blame the caregivers for meddling in family affairs when the social workers find out about patients who are ill-treated.

Some patients refuse to give the caregivers relevant and up-to-date information about their health. They usually hide the recent clinic cards and give caregivers old ones where the health condition was still better. They do this because they want to make the caregiver believe they are not as sick as they look and therefore need not take medication as directed by the doctor or nurse. This is mostly done by patients who have lost hope and do not want to live anymore. It becomes the responsibility of the caregiver to dig more until they get hold of the latest cards so that they can provide a better care service to the patients and also encourage the patients. In places such as Eastern Cape the caregivers need to act as counsellors to such patients and their family members as there are no psychologists who work with them. Caregivers stated that knowledge about the family beliefs and religion comes in handy in such situations. Caregivers from Dutywa often resort to the Bible and prayer as MIDA, the HBHC facility that they work for is a faith-based organisation.

Another major challenge for the caregivers is stigma. Patients are sometimes reluctant to disclose their health status especially HIV status to their family members and even their caregivers because they are afraid of being treated differently at home and in their communities once people find out. This causes concerns as patients do not get a support system and proper care. Caregivers have to build a relationship with the patients and assure them that their discussions are private and confidential. They also encourage them to disclose to their family members and their loved ones to get more support at home. This is confirmed by the literature that shows that this has been an issue in South Africa for a while now. The study conducted by Campbell, Nair, Maimane and Sibiyi in 2008 stigma and unwillingness of patients to disclose limits them to the little care services and support that might be available.

Poverty is also one of the major challenges that the caregivers are faced with in their work. Many patients and their families have no income at all. Even though only a small number caregivers is getting stipends and the rest of them act as volunteers they are always willing to open their hearts and share the little they have with the patients who have nothing. This is a problem that keeps caregivers emotionally engaged even when they are in their own homes, they cannot rest easy not knowing what their patients will be eating. To deal with poverty issues caregivers ask the HBHC facilities they work for to provide food parcels and help the patients to apply for social grants. This problem is not unique to the cases, past research shows that caregivers all over South Africa are faced with the same challenge. According to Campbell, Nair, Maimane and Sibiya (2008) poverty is rife in most communities where caregivers work and many people do not have an income.

Caregivers do their job despite the challenges and problems they face because they love people, are willing to help in their communities and they learn more skills which can be useful for them when they are looking for better jobs with the Department of Health. Some mentioned that they do care giving because they did not have anything else to do when they finished their Matric as they did not have money to proceed to tertiary institutions. Some feel it is a very fulfilling job as they like helping people in the communities and they get stipends.

#### **5.4. Data elements**

This section shows how the questions regarding data elements were answered in the research and what the answers are. These questions are:-

- Which data elements are relevant to HBHC, and to caregivers in particular?
- How are data elements presented on different forms and reports in HBHC
- How are data elements used differently in different communities?

This is done by discussing what the literature and findings say regarding the use of the data elements in different institutions and in HBHC in general. It also looks at the caregiver's perceptions and use of data element. The four lenses that is CoP, community learning, socio-technical theory and social representations are used as lenses to look at the data.

Data elements are very important in patient care. Caregivers use different data elements on the forms. No information could be found regarding the usage of data elements in South African HBHC in the literature. The data gathered during data collection about the use of data elements in HBHC is discussed in the next sections.

#### **5.4.1. Institutional use**

Findings in all three cases show that the HBHC facilities are influenced by DoH and their sponsors on which forms to use. DoH is the main source of funding for paying the stipends of the caregivers in both Eastern and Western Cape Provinces. Therefore the department expects the caregivers to work certain number of hours per day and it has specific information and statistics the HBHC facilities need to report on. The facilities then incorporate all these data elements in their forms to ensure that the information required for example the number of people on TB treatment, HIV positive or on ARVs.

Stellenbosch Hospice has a more organised setting than the two cases in the Eastern Cape, they also have employees that are computer literate and are therefore able to create their own forms. Other funding organisations also give them their own forms. At the end of each month the forms together with monthly reports go to the sponsors and the government departments that the HBHC centres work with. . It is possible that the same information appears on these different reports according to the different requirements of the authorities they report to.

In the Eastern Cape the DoH plays a major role in deciding which forms to use and which data elements should be included on the forms. They provide most of the forms used in MIDA and Ixabiso Lomntu Community Health Care Centre. At the end of each month the forms together with monthly reports go to the sponsors and the government departments that the HBHC centres work with. This poses a lot of problems for caregivers because when the sponsors change the forms change too. The government departments are also continually changing the forms to suit their needs and caregivers need to learn and adapt to those changes.

Caregivers from all three cases get some form of training at the beginning of their work as caregivers to equip them with skills on how to care for patients, how to fill in the forms and use the data elements. The training is usually short and most caregivers do not fully understand how these data elements are used. They learn as

they do the work and rely on their colleagues to guide them when they do not understand. The way caregivers interpret and use the data elements has a huge impact on the way they do the work and report back to the HBHC facilities they work with. The findings show that more training on how the forms and the data elements on them are used is required. Most caregivers interviewed did not know how some of the data elements are used, some had their own interpretations that were not totally in line with what the data elements were intended for.

#### **5.4.1.1. Data elements are relevant to HBHC and caregivers**

The findings show that there are several data elements that the caregivers use. This was determined by asking the caregivers from three cases which data elements they think are important and used daily.

Caregivers from Flagstaff stated that the important data elements for them are patient Name, patient surname, age, gender, contact number, employment details, employment status, source of income, health condition, illness/disease, default status, category, patient history, medication, health facility that supplies treatment and medications, interventions, scope of work, challenges, recommendations, improvements, patient health needs, period on medication, family members, family needs, family health history, support groups, environmental factors, social problems, living conditions, observation, infection control, treatment support, food availability, health risks, medication taken correctly, health facilities visited and CD4 count for HIV positive patients.

For caregivers from Dutywa the important data elements are patient name, patient surname, age, gender, residential address, cell phone number, telephone number, head of the household, no of the family members, challenges, household number, environment factors, category, social problems, patient needs, family needs, environmental factors, social problems, social needs, TB suspect, malnutrition suspect, physical address, date of registration, patient details and family members details.

In Kayamandi the important data elements for caregivers are patient number, patient name, surname, age, gender, residential address, cell phone number, telephone number, category, health condition, illness/disease, medication, age group of the child (e.g. 0-5 years or 6-14 years), support groups, health facility that supplies patient medications, times spent at the patient's home, chronic/palliative, observation, TB adherence, ARV adherence, day care, forum day, elder at home, caregiver name, month of service provision, area, referrals, area meeting and medication delivered.

After analysing the forms and the data collected from the three cases the common data elements identified are: patient Name, patient Surname, Gender, age, cell phone number, category, illness or disease, condition, family members, medication, source of income, patient history, facility where medication is collected and patient needs. Data elements such as household number and home address have different name but are used in the same way. For all areas to understand the data element the researcher would name the data element home address or residential address. TB adherence and ARV adherence are referred to as default status in other areas. The data element is concerned with patients adhering to their medications.

The researcher suggests the three terms should be used. Default status stating whether the patient is a defaulter or not. TB adherence and ARV adherence would then clarify for which medication the patients has defaulted. Dutywa is the only area that used the data element Religion. This is important for the HBHC facility as it operates under a faith-based organisation and the caregivers use this to determine which sort of counselling and encouragement to use for the patient especially the ones who have lost hope.

From the important data elements from the three cases an initial set of core data elements was identified as shown in Table 5.2. These data elements were grouped into section so that it may be easier for the reader to understand which category or section the data elements are in and give an idea of how they are used. The researcher could not find a standard for data element usage internationally as each country uses its own standard. Therefore could not check this core set against the core set of patient data elements as standardized internationally

**Table 5.2: Core data elements used in HBHC**

<b>Patient Details</b>
Patient name, patient surname, age, gender,
<b>Contact Details</b>
Residential (home) address, cell phone number, telephone number
<b>Employment Details</b>
Employment status, employer
<b>Health Details</b>
Category, health condition, illness/disease, default status, patient history, medication, period on medication, health facility that supplies treatment and medications, medication taken correctly, health facilities visited and CD4 count for HIV+ patients, patient health needs,
<b>Family Details</b>
No of the family members, family members, family needs, family health history, head of the of the household, contact details of the head of the household, age group of the child (e.g. 0-5 years or 6-14 years),
<b>Service Provision</b>
Date of registration, observation, treatment support, challenges, TB suspect, malnutrition suspect, support groups, times spent at the patient's home, chronic/palliative, observation, TB adherence, ARV adherence, day care, forum day, caregiver name, month of service provision, area, referrals, area meeting and medication delivered.
<b>Other details</b>
Environmental factors, social problems, living conditions, infection control, food availability, health risks, social needs,

## **5.5. Caregivers' use and perception**

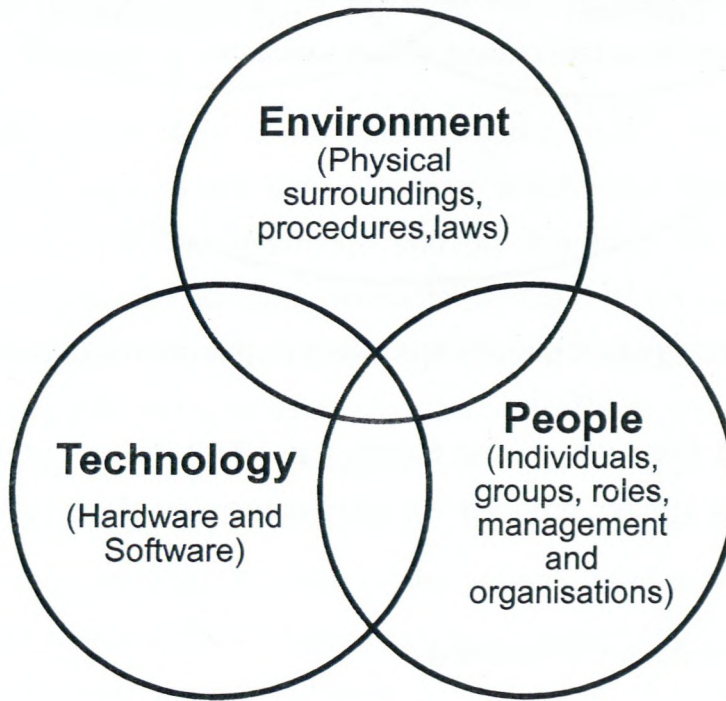
Data elements discussed in the previous section are similar and the way they are used is not that different even though they may have a different names. For example the household number used in Dutywa is similar to the physical or residential address used in Western Cape. Since village homes in Dutywa do not have a house number and a street name, the caregivers and their managers assign a number for the home to identify its location. Another similar pattern is in the use of the data element Category. All three cases use a category and the caregivers stated that it is one of the most important and difficult data elements they use on a daily basis. Category may be defined as the severity of the patient illness. Findings show that there are three categories namely Category 1, Category 2 and category 3 used in both provinces. Caregivers use and understand these differently (see Appendix D).

To understand how caregivers understand and use data elements socio-technical theory was used as lens. This theory, and the categorisation of data elements, is discussed in the section below.

### **5.5.1. Socio-technical Theory**

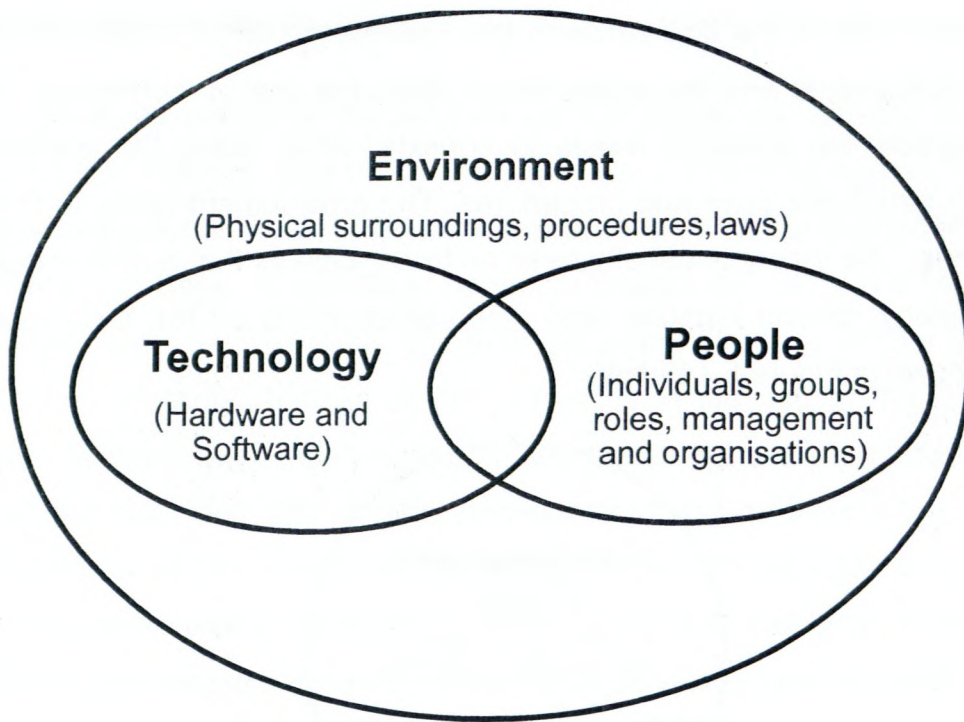
Socio-technical theory was used as a lens to categorise the data. Factors were looked at in terms of environment, technology and people. Socio-technical theory was first introduced by researchers at the Tavistock Institute for a coal mining project in 1949 (Trist, 1981; Ghaffarian, 2011). The theory has been used in several field over the past few decades including in IS research as well as in information Systems Development for Development (ISD4D) and Information and Communications Development for Development (ICT4D) projects. Several researchers such as Avgerou, Bostron and Heinen (Ghaffarian, 2011; Avgerou & LaRovere, 2003; Bostrom & Heinen 1977.) mention a few have looked at the socio-technical perspective in IS development and Innovation over the years the theory has been used and its flaws in ISD were identified. Ghaffarian (2011) states that since socio-technical theory has evolved to focus more on design and attempts to accommodate the interchange between the technical and the social aspects of information systems. Nowadays the theory is mostly used in interpretive and critical research (Palvia, Sharma & Conrath, 2001).

The method looks at the link between the technology, environment and people. It analyses how people and the environment affect the use of technology. There are several aspects the research needs to consider when using this method. These include the structures, laws and procedures. The environment refers to the physical surroundings. The theory is usually seen as three aspects that is technology, people and technology coming together and researchers focus on the area where these meet as shown in Figure 5.1 below.



**Figure 5.1: Socio-Tech Theory Model [Adopted from Shozi, 2012; Trist, 1981; Bostrom & Heinen 1977]**

However in my research I found out that is not always the case. Aspects of both technology and people operate in a specific environment with environmental factors as well as rules and procedures influencing how people use the technology (see Figure 5.2). The social factors also have an influence on the technology.



**Figure 5.2: Technology and people operating in the environment**

Findings show that there are several factors that affect the use of data elements in HBHC and these factors are grouped into three categories of the socio-tech theory as shown below.

#### **5.5.1.1. Technology Component**

The technology aspects that caregivers deal with are the forms with many different data elements. The choice and arrangement of the data element on the forms is done for a specific purpose. For example the HBHC facilities need to ensure that data elements that are important and they need to report on to their sponsors and government departments such as DoH at the end of each month are included on the forms. The description and use of the forms and the data elements on them in technological perspective may differ from the description and use when there is human involvement and therefore social and environmental aspects come into play. Caregivers with different skill and education levels, experiences and cultural background may have a different definitions and understanding of the forms and data elements and in turn the way in which the work is carried out.

There are several aspects regarding the technology that were identified. These aspects are

- **Language** – All the forms used in the three cases are in English (and in Afrikaans in case of Stellenbosch hospice). This is a problem for caregivers who are not good in English as they do not understand what the data elements mean. For most caregivers in all three cases it is a challenge to capture information in English, they are forced to write fewer details about the care service as they do not know how to express themselves in English and other valuable details get lost in translation. This is a big problem for the HBHC facilities as they do not get the full extent of what the situation is at the homes. The data elements are in English and some caregivers do not know their meaning and how they are used.
- **Unclear data elements** – some data elements on the forms are not clear and properly named. There are data elements which have the same name on the forms but have different meanings and are meant to be used differently. An example of this are the two data elements named Date on the patient record used in Dutywa by MIDA Health and Poverty Project caregivers. The first data element refers to the month and year when the care service was provided. The caregivers fill in a form for each patient for one month. The form has spaces to record the care details for each day of the week. The second data element refers to the actual date the caregiver took care of the patient. If the patient was seen once a week for four weeks all these dates have to be written under each day. Such data elements can cause lots of problems particularly for the HBC manager, nurses and administrative staff who need to know the exact dates the care services were provided when compiling monthly care reports.
- **Poorly structured forms** – The forms are not properly structured. Some of the important data elements are not included in the forms or the space provided to capture the details is insufficient. Usually the forms have rows and columns for all these care service details. Caregivers particularly in Flagstaff are forced to write care giving reports as the forms only have few data elements. In some cases there are too many data elements that take the space on the forms as the caregivers hardly use them. Participants stated that they do not even know how such data elements are used as they focus on the ones they use on a daily basis. This emphasizes the importance of and the need to identify the data elements that are relevant to caregivers and customise the forms to suit the needs of each HBHC facility.

- **Incorrect, inaccurate or incomplete information** – Forms have data elements that the caregivers do not know how to use. In such cases caregivers use the data elements according to their understanding which may not always be the correct way. This has a major effect on the quality of care provided to the patients. This was discussed in detail in Chapter 4 (Sections 4.3.2.4., 4.4.2.4 and 4.5.2.4.).
- **Difficulty in doing calculations** – Most forms, such as the tally sheets and caregiver home visit forms, used in HBHC require caregivers to do calculations. The calculations include the number of people seen on TB treatment, ARVs, HIV positive, number of patients on categories 1, 2 and 3, total time spent at the home and many others. Caregivers have difficulty in doing these calculations and always make mistakes.
- **Too much details to be captured** – Some forms used in HBHC contain many data elements and caregivers have to capture too many details. This is time consuming, it takes the attention away from the patient and the caregivers are likely to make mistakes. Other data elements are either redundant or rarely used.

#### 5.5.1.2. Social component

Findings show that several social aspects contribute to the use of forms and data elements in HBHC. These social aspects are discussed below.

- **Language** – Language is the one of the major challenges that the caregivers are faced with in all three cases. Most caregivers are not educated, even with their Matric certificates they cannot speak English fluently and do not know how to express themselves in English. This poses a great challenge as the caregivers need to fill in the forms in English. It also affects the quality of care service provided because the nurses will not know the real situation at the home and therefore necessary improvements will not be done.
- **Education and illiteracy** – Caregivers in both Eastern and Western Cape provinces are not well educated. The highest level they have is Grade 12. In Western Cape Province they have recently made a standard that all caregivers have a minimum of Grade 12 and basic care giving training. However many caregivers were employed before the standard was implemented and they struggle to read, understand and use the forms with complicated data elements.

- In the Eastern Cape the HBHC facilities rely on people volunteering to be caregivers as they do not have funding to pay for everyone. Some volunteers are passionate about helping people in their communities and fairly good in caring for the sick. However most of these caregivers do not have Grade 12 certificate and they struggle with filling in the forms in English. They also do not understand the English reading material they get from the HBHC centres. This is a problem because caregivers have to be up-to-date with health topics pertaining to their work such different illnesses and symptoms, medications and their side effects, vaccines and new methods of caring. They also need to know about social issues such as applying for IDs, birth certificates and social grants.
- **Training** – Training plays a vital role in equipping the caregivers with the necessary skills they need to carry out their care giving tasks. HBHC centres use their limited resources to ensure that caregivers are trained. All three cases differ in the way training is conducted. In Stellenbosch caregivers undergo intensive training at the hospice and their performance is evaluated to ensure that they will be able to do the work at the home and they will be able to deal with problems and pressures arising from that. The caregivers are trained on different aspects when they are appointed as caregivers and on regular basis to ensure they are familiar with new methods of caring, medicines and different illnesses.

In Dutywa, even though they try to train everyone at the beginning, it is usually for a short period and there is no way of knowing how the caregiver will perform once they do the work. In most cases the caregivers have to rely on their colleagues to help them adjust and deal with the problems that arise. They also learn many things on their own. There are few training sessions provided by the DoH and only a small number of caregivers qualify to attend. Also the caregivers need to show some level of skills and abilities to be able to participate in different training programs such as **ancillary training**. The people manage the program have no medical or nursing background. This makes it difficult for the caregivers who rely on them as everyone needs to continually learn. The caregivers in Flagstaff are trained by different organisation, the HBHC centre and personnel from government departments like DoH and DSD. All these perspectives of training affect how caregivers use and understand data elements.

- **Experience** – Findings show that caregivers are passionate and good at caring despite their experience. In both Eastern Cape and Western Cape Provinces experience is not a requirement for those who want to join HBHC, they can learn as they do the work. However those who are experienced understand the work and the forms better and are faced with fewer care recording problems. They understand the data elements better and they are much better in doing statistics as they have been doing them for a longer period. They also handle problems that arise at the home better than those who do not have experience. According to Shozi (2012) the performance of those with experience is much better than those with little or no experience.
- **Dishonesty among patients and their family members** – According to the findings caregivers are faced with the problem of patients and family members who are not honest to the caregivers about their situations. Sometimes they withhold or lie about information that is relevant to the care service such as their health condition. This affects how caregivers make decisions and use the data elements.
- **Lack of trust** – People are not very trusting in all the three communities. Caregivers struggle with trust issues in the communities. People do not feel comfortable to open up to strangers about their health, living conditions and the challenges that they are faced with. Caregivers have to be patient at the beginning and focus on earning the trust of the patients and family members. Even though the care service provision is for the good of the patients, caregivers have to be patient with patients and continue to convince them of the benefits even when they are rejected.
- **Emotional Involvement** – Caregivers are constantly thinking and worrying about their patients. Even when they are at their own homes they are emotionally involved. This may become a burden as the caregivers do not get a break from the work pressure. HBHC facilities such as Stellenbosch Hospice have implemented programs that are aimed at caring for the caregiver and help them cope with caring burden.

### 5.5.1.3. Environmental component

- **Poverty**– Poverty is widespread in communities where caregivers work. People struggle to make ends meet, to an extent that patients and their family members would go to bed without any food. In some cases they do not have money for basic needs such as food. This affects the care process and subsequently the data elements usage as caregivers have to cater for these changes both in the work and care details.
- **Poor roads, sanitation and housing and lack of electricity and piped water** – Another biggest challenges in the communities particularly in Eastern Cape is lack of access to basic necessities such as clean running water, proper sanitation, roads and electricity. This has an effect on the work the caregivers do. In most cases the caregivers work is added in these communities as they need to assist their patients with fetching water from nearby taps and rivers. The case also need to teach
- **Stigma** - stigma is one of the major problems in both provinces. Caregivers have to be cautious with patient forms and due to the confidentiality and privacy of the information in them. In Kayamandi area caregivers do not write the names of the patients on the forms that they carry when visiting. They only write the patient number and the address to ensure that in case the forms get lost and land in wrong hands the patient information will remain private as people will not know who actually the patient from that home is. Patients and the family members in Kayamandi area have to ensure that no one has access to the patient record that is left at the home. Patients are also not very open about their illnesses because they are afraid they will be discriminated against if people in the community know about their health conditions.
- **Long distances between patients' homes** – Caregivers walk long distances between patient homes because the HBHC facilities that they work for do not have enough funding to cover transportation. They work in all sorts of weather, from blazing heat to freezing temperatures. By the time they reach the patient homes they are either too tired or too cold but they still need to do the work. They carry with them the forms where they fill in care service details.

- **Lack of resources and supplies** – According to the findings the HBHC facilities in Eastern Cape are struggling, they do not have sufficient resources and supplies to carry out the work. The caregivers need to improvise when they run out of supplies such as bandages, ointments, anti-bacterial solutions. The use of indigenous knowledge has proven to be valuable in resource-limited settings. Caregivers use their indigenous knowledge in these cases for example a caregiver stated that when they are out of supplies and need they would use warm water with salt to clean a patient's wound.
- **Lack of or limited funds** – The HBHC facilities particularly in Eastern Cape Provinces are struggling to get funding. This has an impact on the day-to-day running of the HBHC facilities. According to the findings the HBHC facilities rely mostly on the help of the people in the communities such as volunteers. These people help to care for the patients without any payment. Sometimes they have to take money out of their pockets to help the people they care for. The caregivers assist the people with food, transport money to the healthcare facilities and they pay for their own transport when they fetch the medication from the clinics and hospitals. Stellenbosch Hospice is well funded and all the caregivers employed are receiving stipends. The HBHC facility also assists people in the communities with food parcels which are delivered daily to the homes.

Using the socio-technical theory as a lens has been very helpful for the study. It helped the researcher to understand all environmental, technological and social issues. Through the use of the theory a clear connection and effect of environmental and social factors on the use of technology has been made. It is important for the study to understand the type of environment the caregivers operate in, the type of people they work with, other social factors that affect their work, the type of technology available to them and how they use and understand this technology.

## **5.6. The role of IK**

IK plays a very important role in caregivers day-to-day activities especially in resource limited settings. In all three cases it is evident that the way caregivers do their work, understand and use data elements is influenced by indigenous knowledge. The findings also show that caregivers' understanding is influenced by their level of education, experiences and indigenous knowledge whether from one generation to another or within their peers. Caregivers carry out their work the best way they know. There are other aspects that have an influence such as individual and group perceptions, shared activities and local perception. These are discussed on the sections below.

### **5.6.1. Social representation**

To understand the individual and group perceptions about data elements and IK social representation was used as a lens. Social representations theory is a "model which focuses upon processes of interpersonal communication as the determiners of the structure and content of the belief systems which are called social representations" (Breakwell, 1993). The theory describes how people come to interpret and make their world meaningful (Breakwell, 1993). Social representations "reflect the practical, everyday knowledge of the ordinary person rather than expert or scientific knowledge" (Walmsley, 2004). According to Moscovici (1984) social representations "are formulated through action and communication in society" and are "a specific way of understanding and communicating what we know already".

The social representations theory acknowledges "human beings as 'thinking persons,' capable of asking questions, seeking answers, and, in general, thinking about life" (Moscovici, 1984; Walmsley, 2004). In HBHC caregivers ask questions, try to find meaning of the things they come across in their work and their daily lives. They then form their social representations based on their work, experience and interaction with other stakeholders in HBHC.

### **5.6.2. Communities of practice**

Communities of practice has been used a lens to look at the shared activities of caregivers in HBHC. Wenger and Snyder (1999) define CoP as “groups of people informally bound together by shared expertise and passion for a joint enterprise.” In HBHC caregivers form CoP where they share their experiences, seek assistance with activities they are not familiar with or ask for advice to make better decisions. Like in a typical CoP, caregivers may or may not have an explicit agenda on a given week (Wenger & Snyder, 1999). In fact caregivers share their experiences in a ‘free-flowing manner’, coming up with creative and easy ways of dealing with problems. Caregivers’ CoP plays a vital role in the work of caregivers. Caregivers learn on the job and within their CoP about the job and doing it better and any new skills they might require in future.

In Kayamandi area caregivers meet every morning before they commence with work and at the end of each day to discuss work and the challenges they were faced with. It is in these meetings where caregivers share their experiences, show each other how to fill in the forms, calculate the numbers on tally sheets and come up with solutions to the problems they come across when doing the work. In other areas caregivers discuss work and issues whenever they get a chance. This may be any time of the day, when they walk to the different patients’ homes or when they have their weekly meetings at the HBHC facility. During the meetings at HBHC facility caregivers get a chance to interact and learn from caregivers who live and work far from their own areas, the nurses and their managers. Caregivers also share their indigenous knowledge about the caring and understanding the forms and data elements on the forms. In both provinces Xhosa women are routed on their indigenous knowledge. They include it in their daily lives hence it is not surprising that IK influences their understanding and the care service they provide to the patients.

### 5.6.3. Community learning

Caregivers from all cases recognise that they are part of a community. During interviews some participants stated that they started working as caregivers because they wanted to help people in their communities. The term community has several definitions; researchers focusing on community research have been writing about it for decades now, however there is no standard definition yet. Community can be defined “as a geographical boundary or group of people who have similar interests, purposes or values” (Falk & Harrison, 1998). Various researchers classify a community as a “learning organisation” (Moore & Brooks, 1996), as an ‘area of development’, such as rural development (Shortall & Shucksmith, 1997) or as a group of ‘pro-active people’ (Topolsky, 1997).

Members of the community need to be emotionally safe, have the same or agree with the values of a community, want to invest in the community, are influenced or have an influence on the community and feel that they belong to the community (McMillan & George, 1986). Even caregivers who were not born in the specific community have a sense of belonging. This is particularly important in HBHC work as patients are not very welcoming to strangers. Things are better for caregivers who were born or grew up in the area than people who just relocated because of work, particularly in rural areas. Old members of the community understand the community better but the new members bring more skills, expertise that is required for development.

There are different important stakeholders in a community and each stakeholder plays a vital role in community learning and development. For example in both cases in Eastern Cape the chief and headman of each village plays a great role in HBHC service provision, improvement of social and environmental conditions of the people. The chief and headman are the authority figures in the village, they grant permission to the caregivers, nurses and HBHC facility managers to approach people for care service provision and host awareness campaigns and health promotion activities. These authorities also ensure the safety of caregivers in the village when they do the work. If there are people who threaten the safety of caregivers they are reported to the chief or headman who then intervenes.

The other stakeholders in the community are teachers, church members and the general members. They all work together with caregivers, nurses and HBHC managers in community learning and development. The community learning activities include health promotion, social, economic and environmental issues. Caregivers also play a big part in assisting students with homework and encouraging them to go to school. In Kayamandi area during interviews one participant stated that sometimes children leave school to care for their sick family members but as caregiver they cannot stand seeing these children being denied an opportunity to be educated. So in such cases, they intervene, assist the sick family members so that the child can go to school. They also ask neighbours to assist as the caregivers cannot spend the whole day at one patient's home. This shows that caregivers see themselves as part of the community and they sincerely care about the wellbeing and development of the community members.

#### **5.6.4. Indigenous knowledge (local perception and experience to be captured)**

IK is functional in scope and serves the individual as part of a greater community purpose (Youngblood, 2010). Even though indigenous knowledge about traditional medicine, herbs and treatment of minor ailments has a significant part in people's lives particularly in resource limited communities (Dahlberg & Trygger, 2009) the HBHC managers are still sceptical about using it during care service provision. In both provinces findings show that caregivers cannot do as they see fit, they are required to ask for permission to use traditional medicines and herbs from their managers as the managers fear traditional medicines would endanger the patients. In Western Cape Province caregivers are given a little room to use their indigenous knowledge. Findings show that in Western Cape caregivers are allowed to use simple remedies, mostly from the pamphlets they get during workshops and training sessions. Little IK may be used for example a caregiver can replace buchu water with warm water and salt to clean wounds. Caregivers cannot use traditional medicines and herbs at all even when they know it would help. They do not use it because they do not want to be in trouble with their authorities. Some stated that they usually use herbs such as umhlonyane, iboza, impepho, ukrakrayo in their own lives but not during care service provision. All these herbs are very common amongst Xhosas in both Eastern and Western Cape Provinces. Umhlonyane is *Artemisia Afra*, commonly known as African Wormwood, in English, Wilde Als in Afrikaans which is used to treat

cough, flu, colds, nasal congestion and chest and stomach issues. Iboza is *Tetradenia Riparia* commonly known as Misty Plume Bush or Ginger Bush in English, Gemmerbos or Watersalie in Afrikaans. It is used mostly for relief of chest complaints, stomach ache, malaria and headaches. Ukrakrayo is *Phylacca Heptandra*, a bitter herb used for stomach complains such as bloating, indigestion and can be used as a laxative. Impepho also known as *Helichrysumkraussii*, is an aromatic plant that is used as incense when dry. All these herbs are stated in many studies conducted on South African herbs and traditional medicines.

Caregivers from Dutywa use their indigenous knowledge to identify those who may be suffering from TB or malnutrition. One participant stated that there are several symptoms they look for to see if the patient has TB such as sweating at night, loss of appetite, coughing and loss of weight. For patients who are malnourished the indigenous knowledge comes in handy because the caregivers do not have equipment to weigh the patients. In such cases caregivers look at the colour and texture of hair, skin appearance, and the normal child's activity. According to them the hair of the child who is underweight becomes thin and reddish, the skin becomes dry and dull, the child would have a big head and tummy and small limbs and also appear sickly. The caregivers stated that they do not need to weigh these patients because the signs are already there. They just refer the children to health facilities for confirmation and treatment.

Caregivers from both Eastern and Western Cape Provinces stated that they also use their indigenous knowledge to make mixtures to prevent dehydration on patients who have diarrhoea. The mixture is made of boiled water, sugar and salt. They also use a mixture of warm water and salt to clean wounds. According to participants this helps prevent infection and make the wounds dry so that they heal quicker. For cough they also use a mixture of honey, ginger and water or freshly squeezed lemon juice in hot beverages such as tea.

## **5.7. Conclusion**

The chapter discussed the findings in Chapter 4. It focused on why things happen the way they do. The next chapter entails conclusion of the study, recommendation and possibilities for further research.

## **CHAPTER SIX**

### **6. Conclusion and Recommendation**

#### **6.1. Introduction**

This chapter includes the overview of the study, the research questions and how they were answered in the study and checks if the goals and objectives were achieved. Limitations and challenges experienced during the research process are also outlined in this chapter. The researcher also reflected on the whole research process and critiqued her work. The validity of the study and the way forward is also discussed in the chapter.

#### **6.2. Overview of the study**

The purpose of the study is to explore the relationships between and approaches to data elements in HBHC. The objectives are to describe the use and presentation of data elements in different HBHC providers, identify or define an initial set of data elements for HBHC, identify or define a core set of data elements for HBHC from the care forms, describe the differences in the use of data elements in differing HBHC contexts, harness caregivers' indigenous knowledge of their interactions with data elements and identify or define a core set of data elements for HBHC based on the care service provision in different communities.

Chapter 1 provided an introduction and background to the study. The main question, sub question and objectives were outlined in this chapter. The problem was clearly shown and different terms were explained so that the reader gets a clear picture of what the study is about. The research process and design including the research approach, data collection methods for the study were also briefly described. Chapter 2 focused on the literature review. The distinction between developed, developing and underdeveloped countries and their healthcare systems were discussed. The African healthcare sector particularly South African healthcare sector which comprises private and public healthcare and HBHC were discussed. The chapter also discussed HBHC, care recipients, IK, data elements, caregivers and challenges that they are faced with. Because topics such as indigenous knowledge are complex and can confuse readers, a clear distinction of what IK means for the study was made. The chapter includes the theoretical framework for the study showing that the study focuses on the area where healthcare, indigenous knowledge, care

stakeholders and use of information meet. The framework shows the theories such as social representation, socio-technical theory, community learning and CoP that are used as lenses to analyse and categorise the data.

Chapter 3 contains the methodology for the study. The research design and process is discussed in detail. The study used three case studies from Stellenbosch Hospice in Western Cape Province, Ixabiso Lomntu Community Health Centre and MIDA Health and Poverty project in Eastern Cape Province. All these three cases were discussed in detail. The selection of cases and participants and the methods used for data collection are covered in the chapter.

Chapter 4 and 5 show the research findings and the discussion respectively. In chapter 4, each case is described fully and the findings for each case are shown. At the end of each section the findings for each case are summarised. Chapter 6 contains the conclusion, answers to research questions and recommendations. The limitations and validity of the study and also the reflection of the researcher are included in the chapter.

### **6.3. Research questions and objectives**

This section looks at the main research question, the research sub questions and how they were answered and also discusses how the objectives were met.

#### **6.3.1. Research question 1**

The first question focused on the data elements that are relevant to caregivers and HBHC in general. The objective was to describe how the data elements in three cases are presented and used and also to identify to initial set of data elements (see Table 6.1). To answer this question samples of all the forms used in three cases were collected. The researcher analysed the forms and the data collected during data collection. The conclusion was all the cases use different forms with mostly similar data elements. All the three cases are influenced by their sponsors on which forms to use and which data elements to use. There are similar data elements such as the category which is used by all three cases and is seen as one of the important data elements. Some data elements are used the same way even though the names are not the same. There are few different data elements such as achievements and recommendations. Ixabiso Lomntu is the only case that used these data elements.

<b>Table 6.1.: Research question 1</b>		
<b>Sub questions</b>	<b>Research method(s)</b>	<b>Objectives</b>
Which data elements are relevant to HBHC and caregivers in particular?	Literature review , initial observations in CPUT project, interviews, focus groups and participant observation	Describe the use and presentation of data elements in three HBHC providers Identify or define an initial set of data elements for HBHC

<b>Table 6.1.2 Core data elements used in HBHC</b>
<b>Patient Details</b>
Patient Name, patient surname, age, gender,
<b>Contact Details</b>
Residential (home) address, cell phone number, telephone number
<b>Employment Details</b>
Employment status, employer
<b>Health Details</b>
Category, health condition, illness/disease, default status, patient history, medication, period on medication, health facility that supplies treatment and medications, medication taken correctly, health facilities visited and CD4 count for HIV+ patients, patient health needs,
<b>Family Details</b>
No of the family members, family members, family needs, family health history, head of the of the household, contact details of the head of the household, age group of the child (e.g. 0-5 years or 6-14 years).
<b>Service Provision</b>
Date of registration, observation, treatment support, challenges, TB suspect, malnutrition suspect, support groups, times spent at the patient's home, chronic/palliative, observation, TB adherence, ARV adherence, day care, forum day, caregiver name, month of service provision, area, referrals, area meeting and medication delivered.
<b>Other details</b>
Environmental factors, social problems, living conditions, infection control, food availability, health risks, social needs,

The findings showed that most data elements the caregivers use are relevant to them and HBHC as a whole. The initial set of core data elements was identified by looking at the responses the participants gave regarding the important and difficult data elements. This set was compiled in Chapter 5, Sub section 5.3.2.1. and is repeated here as is shown in the Table 6.1.2 above.

**6.3.2. Research question 2**

<b>Table 6.2.: Research question 2</b>		
<b>Sub questions</b>	<b>Research method(s)</b>	<b>Objectives</b>
How are data elements presented on different forms and reports in HBHC?	Initial observations, document analysis, interviews, focus groups and participant observation	Describe the use and presentation of data elements in three HBHC providers  Identify or define a core set of data elements for HBHC from the care forms

The second sub question looked at the presentation of the data elements on different forms and reports in HBHC. The findings show that the data elements on the forms and reports from the three cases are presented and structured differently. Each HBHC facility uses its own set of forms and reports that suit their needs and the needs of their sponsors and the government departments they work with. In Stellenbosch forms are detailed, each form used has a clear purpose and most of the data elements on them are relevant and used regularly. However this is not the case in Eastern Cape particularly in Flagstaff. The forms used in Ixabiso Lomntu Community Health Centre are few and the data elements on them are not adequate to record details of the care service. Caregivers are required to write additional reports. Also the structure of the forms is not good; the space is usually inadequate to write details even if the data element is on the form. This case is not unique to Dutywa; it is a problem for all cases. In both cases in Eastern Cape some data elements are confusing as they have the same name but used differently or in different sections. Socio-tech theory was used to categorise and analyse the use of data elements. The technological, social and environmental factors that affect data elements and the forms are discussed in Chapter 5.

### 6.3.3. Research question 3

<b>Table 6.3.: Research question 3</b>		
<b>Sub questions</b>	<b>Research method(s)</b>	<b>Objectives</b>
What is the significance of indigenous knowledge regarding the use of data elements?	Observations, focus groups	Explore the role of indigenous knowledge in the daily care service process

Research sub question 3 is: what is the significance of indigenous knowledge regarding the use of data elements and the objective is to explore the role of indigenous knowledge in the daily care service process as shown in Table 6.3. The question was answered by looking at the role indigenous knowledge plays in HBHC during care service provision and how it affects the way caregivers use and understand data elements. Findings show that caregivers use their indigenous knowledge when they provide care services but this is limited to what their facility allows. This IK plays a major role particularly in resource limited settings where caregivers needs to constantly improvise to ensure that patients get proper care services. Findings show that other factors such as education, training and experiences also has an influence in the use of data elements and service provision.

### 6.3.4. Research question 4

Research sub question 4 focused on how IK can be better utilised and captured for an effective care service provision and data element usage. The objective here was to harness caregivers' IK of their interactions with data elements in a repository and analyse the captured IK to identify patterns of use.

<b>Table 6.4.: Research question 4</b>		
<b>Sub questions</b>	<b>Research method(s)</b>	<b>Objectives</b>
How may indigenous knowledge be better utilised (e.g. captured) in terms of more effective data element usage?	Interviews, focus groups and participant observation	Harness caregivers' indigenous knowledge of their interactions with data elements Analyse the captured indigenous knowledge to identify patterns of use

To answer research question 4 participants responses were analysed and discussed in Chapters 4 and 5 and can be summarised as follows: IK has a lot of value among Xhosas particularly in rural areas and resource limited settings. However HBHC managers are still reluctant to incorporate it in their caring strategies. HBHC managers should take advantage of it because it can help yield better results regarding the care.

### 6.3.5. Research question 5

<b>Sub questions</b>	<b>Research method(s)</b>	<b>Objectives</b>
How are data elements used differently in different communities?	Initial observations, interviews, focus groups and participant observation	Describe the differences in the use of data elements in differing HBHC contexts Identify or define a core set of data elements for HBHC based on the care service provision in different communities.

Research sub question 5 focused on the differences and similarities in data element usage in different communities. The objectives were describe the differences in the use of data elements in differing HBHC contexts and also identify or define a core set of data elements for HBHC based on the care service provision in different communities. Using interviews, focus groups and participant observation the data about the usage of data elements in three cases was gathered then analysed. Results (in Chapter 4 and 5) show that there are similarities in the way caregivers use data elements in one HBHC facility and other communities. Some data elements are the same and the way they are used by caregivers from the three cases are similar. There are fewer data elements which are different. There are also some differences in the way caregivers from one case use the data elements used in other cases. For example **category** is a data element used by all three cases. During data collection caregivers gave their understanding of the data elements. Caregivers from Kayamandi are the only caregivers that look at the number of digits of the patient number to determine which category the patient is on.

### 6.3.6. Research question 6

<b>Table 6.6.: Research question 6</b>		
<b>Sub questions</b>	<b>Research method(s)</b>	<b>Objectives</b>
Which differences occur in terms of indigenous knowledge uses?	Initial observations, interviews, focus groups and participant observation	Describe the differences in the use of data elements in differing HBHC contexts Identify or define a core set of data elements for HBHC based on the care service provision in different communities.

The last research question looked at the differences in IK usage in all three cases. The objectives were describe the differences in the use of data elements in differing HBHC contexts and identify or define a core set of data elements for HBHC based on the care service provision in different communities as shown in Table 6.6. The findings and discussion in chapters 4 and 5 show that there are some similarities in the way IK regarding data elements is used in all three cases. IK is essential during care service provision in all three cases and it affects the way the caregivers understand data elements and in turn do the work. There are also similarities regarding IK such as traditional medicines. HBHC managers of all three cases do not encourage the use of traditional medicines or medicinal herbs that that caregivers normally use in their lives and their families. Caregivers are allowed to use mixtures and remedies recommended on their training and workshop pamphlets. The two cases in Eastern Cape are stricter regarding the usage of IK than Western Cape. In Kayamandi caregivers are given a little room to do think and use their IK as long as it does not harm the patient.

### **6.3.7. Main research question**

The main question for the study is: What happens when caregivers from various communities interact with data elements when providing a care service? The researcher arrived to the answer for this question by taking the key points that relate to this question from the sub questions. This answer may be summarised as follows:

The caregivers from the three cases interact with data elements during care service provision at the patient home and after in their homes. There are several activities that take place when the caregivers interact with the data elements. The caregiver may be influenced by the data elements on what sort of action to take. These data elements that determine the course of action for the caregivers the researcher refers to as the important, key or core data elements. These data elements include the patient category, the illness, people that reside at the patient's home. The caregiver also has an influence on how a certain data element is used. This is caused by factors such as caregivers' experience, education, level of skills and understanding.

Another important question that the research answers is: what is the role of indigenous knowledge in caregiver activity, and how does one move toward an approach for capturing and sharing this knowledge in terms of data elements? Currently the role of IK during the care service is massive. Caregivers 'use' their IK in understanding and using their data elements during care visits. The knowledge is shared among caregivers in CoP and with the community and other HBHC stakeholders.

### **6.4. Limitations of the study**

The research focused only on three cases, therefore cannot generalise beyond three cases as each case is unique. The study was wide and extensive; therefore not all the issues were covered during the interviews. It was never the intention to generalise the findings since the aim of the study was to explore the caregivers' interaction with data elements. Since it was not clear to what extent the contextual aspects would be relevant it was decided to rather do in-depth case studies which can then provide the basis for further studies.

#### **6.4.1. Translation**

Translation and transcription from Xhosa to English was tedious and time consuming. It took over two months. Even though the researcher understands and speaks the language some words are difficult to translate to English as Xhosa is complex. Even with the assistance of other people the researcher had to go over all the translation and redo some as Xhosa spoken in different areas of South Africa differ. Proper care had to be taken to avoid loss of important details during translation.

#### **6.4.2. Language barrier**

Supervisors do not speak or understand Xhosa, therefore they could not read or comment on the data before translation and transcription could be done. They also had to rely on the researcher to translate the data correctly. Xhosa language is complex, the researcher struggled to get assistance in translating and transcribing the data because even though the people who were available to assist understand and speak Xhosa they did not understand some caregivers particularly the ones from Flagstaff as they used their local dialect namely Pondo during the interviews.

#### **6.4.3. Caregiver availability**

There were fewer caregivers available for interviews than the researcher intended particularly in case 1. She had to work with the available number of caregivers as the others were working in the villages far from the HBHC centre where the interviews were conducted. Also, the number of experienced caregivers was fewer than anticipated.

#### **6.4.4. Distance, weather and transport issues**

Data collection could not be done over a long period due to the distance where the distance and the schedule of the participants. Due to bad weather and lack of transport to the villages in Dutywa, the participants were requested to go to the HBHC in town where the interviews were conducted and they were compensated for the transport. The interviews had to be done in one day and the caregivers had to be allowed to leave on time to catch transport back to the village. This meant that the duration of each interview would be shorter.

## **6.5. Validity and reliability of the study**

Triangulation was used to increase validity and reliability of evaluation of research findings. Triangulation is a strategy which uses more than two “data sources and methods to lead to a singular proposition about a phenomenon being studied” (Mathison, 1988). In this study methodological triangulation which involved using various methods to collect data such as interviews, focus groups, participant observation and document analysis was implemented. Methodological triangulation was useful as the researcher got to explore the strengths of each data collection method while the other methods covered the weaknesses of another. When researchers use “multiple methods they achieve the best of each while overcoming their unique deficiencies” Denzin (2009).

Klein and Myers (1999) introduced seven principles of conducting and evaluating interpretive field studies in information systems. These seven principles focus on interpretive studies of hermeneutic nature. The principles were used in the study to ensure that the data collected is of high standard and is interpreted correctly. The principles were introduced briefly in Chapter 3 and are discussed in detail in the next section.

### **1) The fundamental principle of the hermeneutic circle**

According to Klein and Myers (1999), this is the most fundamental principle of the hermeneutic circle. It lays a foundation for all interpretive work with hermeneutic background and all the other six principles are built upon it. “The principle suggests that all human understanding is achieved by iterating between the interdependent meaning of the parts and the whole that they form” (Klein & Myers, 1999).

This principle was applied in the study extensively. Data collected from the interviews and focus groups was analysed during the translation and transcription. This was done to understand the data as a whole and then group it accordingly so that individual parts would also be clear. The analysis went further until the data was put into themes. Also the data from participant observation and document analysis was included.

## **2) The principle of contextualisation**

The principle is about seeking meaning in context. The principle of contextualisation principle necessitates critical reflection of the social and historical context so that the readers can see how the current situation under investigation emerged.

This principle was applied thoroughly. For the researcher to understand the general use of data elements in HBHC, there was a need to interpret each case. During data collection the researcher included questions that focused on understanding the context. The question included the process caregivers go through when they do the work, challenges they are faced with, the type of people they deal with, the lifestyle of people in the areas where they work, factors that encourage or influence them into working as caregivers, the language, experiences, education and skills of caregivers. All these questions helped the researcher to understand each case better. Before the findings were presented in Chapter 4 each case was described.

## **3) The principle of interaction between the researchers and the subjects**

This principle “requires critical reflection on how the research materials (or “data”) were socially constructed through the interaction between the researchers and participants” Klein and Myers (1999). Interpretivism suggests that the facts are produced as part and parcel of the social interaction of the researchers with the participants.

The researcher was involved and interacted with the subjects or participants throughout the data collection process. The researcher approached all the HBHC managers in person to ask for permission to collect data for the study. All the participants were interviewed in their home language as it was important for the study to get the rich data and not lose it in translation. The researcher made the participants comfortable to talk about their job in detail.

#### **4) The principle of abstraction and generalisation**

The principle of abstraction and generalisation "requires relating the idiographic details revealed by the data interpretation through the application of principles one and two to theoretical, general concepts that describe the nature of human understanding and social action" Klein and Myers (1999).

The study looked at three cases; some of the findings coincide with the literature. One can fairly generalise in resource limited settings in Western and Eastern Cape Provinces as the cases are very similar. However generalising throughout South Africa is not advisable as the other cases maybe unique.

#### **5) The principle of dialogical reasoning**

The principle of dialogical reasoning requires sensitivity to possible contradictions between the theoretical preconception guiding the research design and actual findings ("the story which the data tell") with subsequent cycles of revision.

Applying this principle was simple because the researcher did not have any prior knowledge about use of data elements in HBHC and caregivers IK. However the researcher needed to keep an open mind about the context and the work of caregivers especially in Eastern Cape since she had been working on another research and development project before with Stellenbosch Hospice.

#### **6) The principle of multiple interpretations**

The principle of multiple interpretations requires sensitivity to possible differences in interpretations among the participants as are typically expressed in multiple narratives or stories of the same sequence of events under study. Similar to multiple witness accounts even if all tell it as they saw it.

The study involved over 26 participants and in some cases there were over 10 participants from one HBHC facility. The researcher applied the principle of multiple interpretations as there were several versions of the same story. The study requires the researcher to look at individual responses and group responses of caregivers from the other HBHC facilities.

## **7) The principle of suspicion**

The principle of suspicion requires sensitivity to possible "biases" and systematic "distortions" in the narratives collected from the participants.

This is one of the tricky principles that one needs to apply in research. The researcher has to ensure that the responses given by participants are truthful and have not been deliberately altered to mislead the study. This was done by using different methods of data collection and involving several participants in the study. Participants were asked questions in focus groups where they were allowed to answer freely, then individual interviews were conducted. The researcher can fairly say that the responses were truthful as all the other methods of data collection delivered similar data.

### **6.6. Contribution of the research and the way forward**

This study is significant because it provides a description of how caregivers use data elements in Home-Based Healthcare and adds to the limited research in South African HBHC. An initial set for core data elements for HBHC has been identified. The collected IK has been captured and stored in a repository and patterns of use and meanings of data elements have been identified. The study will also be useful for HBHC service providers and people who develop the services so that they can caregiver training accordingly. Government can use it to understand the difference between care records and patient record.

### **6.7. Recommendations**

More training and different translations of the forms as people do not understand English are recommended. It is advisable that HBHC facilities allow caregivers to capture the care service details in their indigenous languages as rich details get lost in translation. The HBHC facility could employ a translator to translate caregiver reports and aggregate these for other reports to different sponsors and government departments. Openness in use of IK by caregivers is recommended as results show that HBHC facilities can benefit from the use of IK.

In 2010 Youngblood (Youngblood, 2010) stated that IK is at risk of being corrupted, lose its value, trustworthiness and detail and even being outright lost. Today this is still a concern, therefore the use of computer based knowledge systems to store indigenous knowledge is recommended. The Kujali project at CPUT has already started developing a knowledge base for IK in healthcare, further work is recommended. Appendix D shows experiences of using such a repository, developers can look at it and improve the repository accordingly to ensure that it is easy to use for those who will capture and store the IK in it. Organisations and institutions such as Council for Scientific and Industrial Research (CSIR), other research institutes and researchers can be involved in gathering, capturing and disseminating IK used in HBHC throughout the country as there is a lot to be learnt from using IK and traditional knowledge.

The initial core set of data elements have been identified. Further research is required to have an accurate set that will be usable throughout the country.

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## **APPENDICES**

### **APPENDIX A: Caregiver Interview Questions**

1. What is your role as a caregiver in HBHC?
2. How many patients are you responsible for in total?
3. How many patients do you see per week/day?
4. How do you organise your daily route when visiting the patients
5. How long have you been working as a caregiver in your organisation?
6. Did you have any experience as a caregiver prior your current organisation?
7. Have you had any training on how to provide a care service to the patients and fill in the forms?
8. Which forms do you use when providing a care service?
9. How do you use these forms? Could you kindly take me through the forms and explain?
10. What does the data elements on different forms mean to you?
11. Are there any data elements that you do not understand or difficult to work with?
12. What do you do you when you have difficulty in working with data elements?
13. Which data elements do you feel are important?
14. What are the problems and challenges do you face as a caregiver?

## **APPENDIX B: Coordinator Interview Questions**

1. What role do you play as the manager?
2. What kind of services do you provide in your organisation?
3. How do you select the caregivers who work in your organisation?
4. How many caregivers do you have?
5. How does your organisation identify patients that are in need of care?
6. How many patients do you currently have?
7. How do you compile a care plan?
8. Which forms are important when caring for patients?
9. Who decides which forms should be used?
10. How do you choose the data elements to include on these forms or which format these forms should follow?
11. How do you use these data elements? Could you please take me through them and explain?
12. Why do you use these data elements the way you use them?
13. Who do you report to as the organisation?
14. How do you deal with reporting and statistics? How often do you do this?
15. Do you provide training to caregivers when they start working for the organisation?
16. Do you sometimes visit the patients to see if the caregivers do the work as well as they should?
17. How is your relationship with the caregivers?







## APPENDIX D: Using the meta-data / IK repository

The data about how caregivers from the three cases were captured in a metadata repository. The tool was developed by one of the masters at CPUT using Visual Studio 2010. On the main screen (see Figure 6.1.) the user sees the different options, the names and contact details of the HBHC facilities on the repository. The user can see other options such as manage initiative, manage sources and manage metadata.

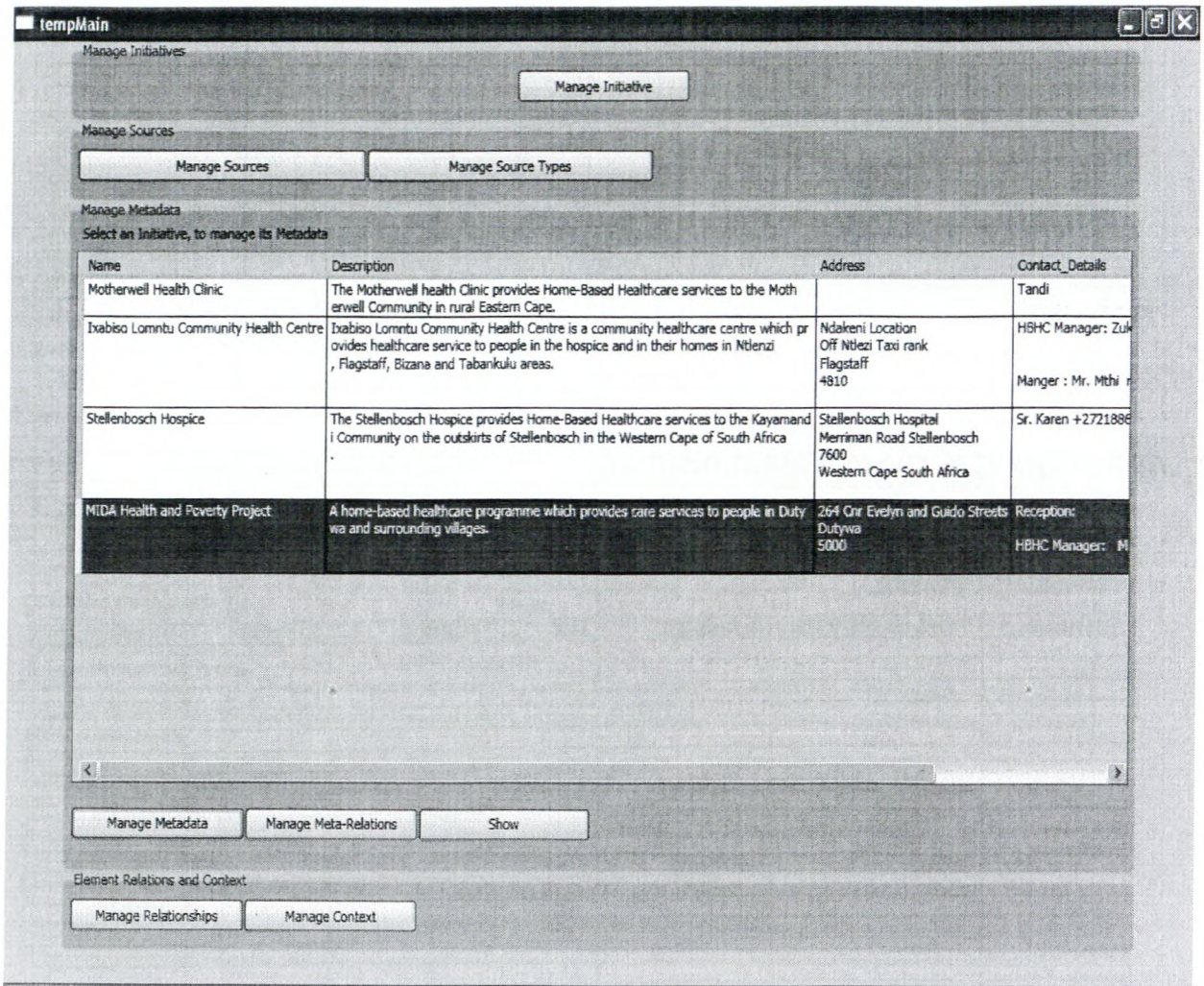
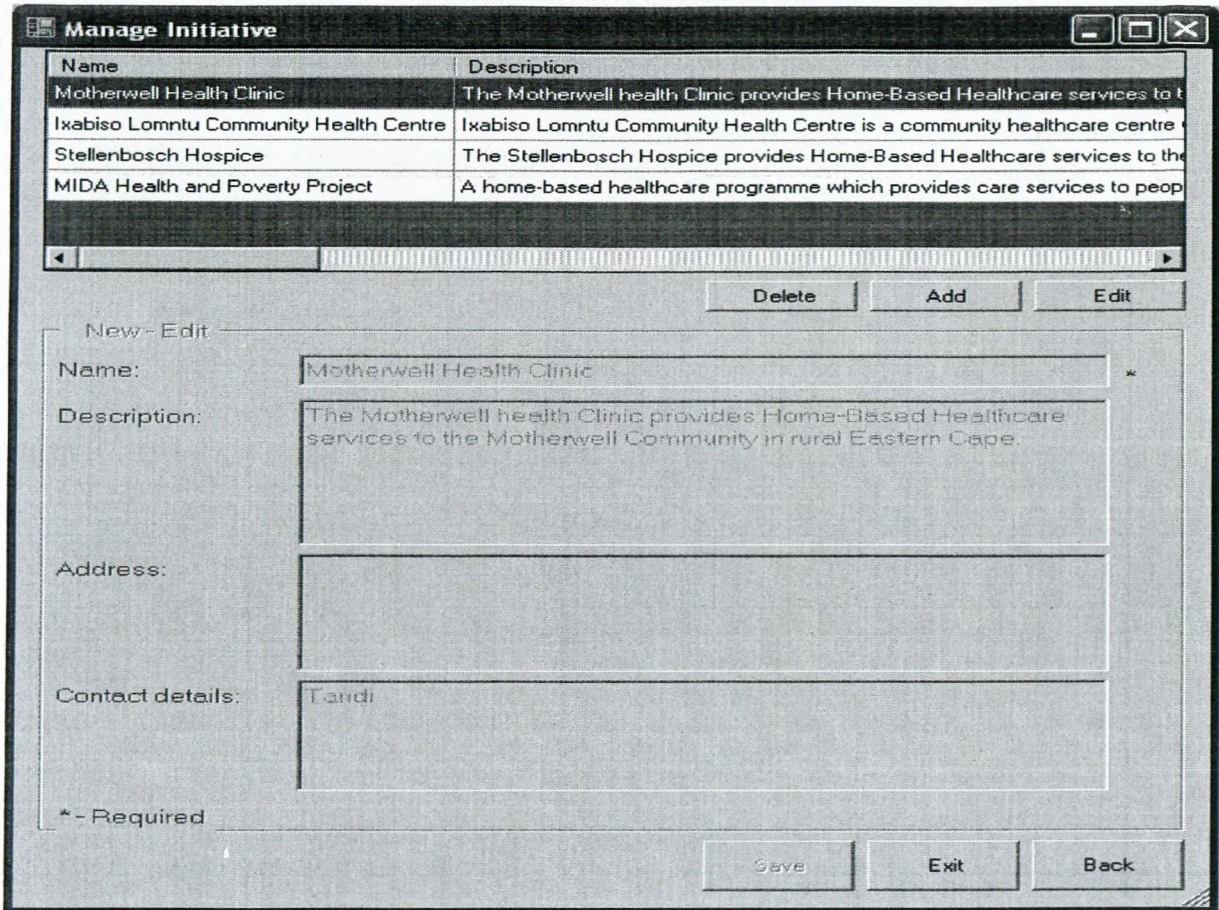


Figure D.1. Main screen of the metadata repository

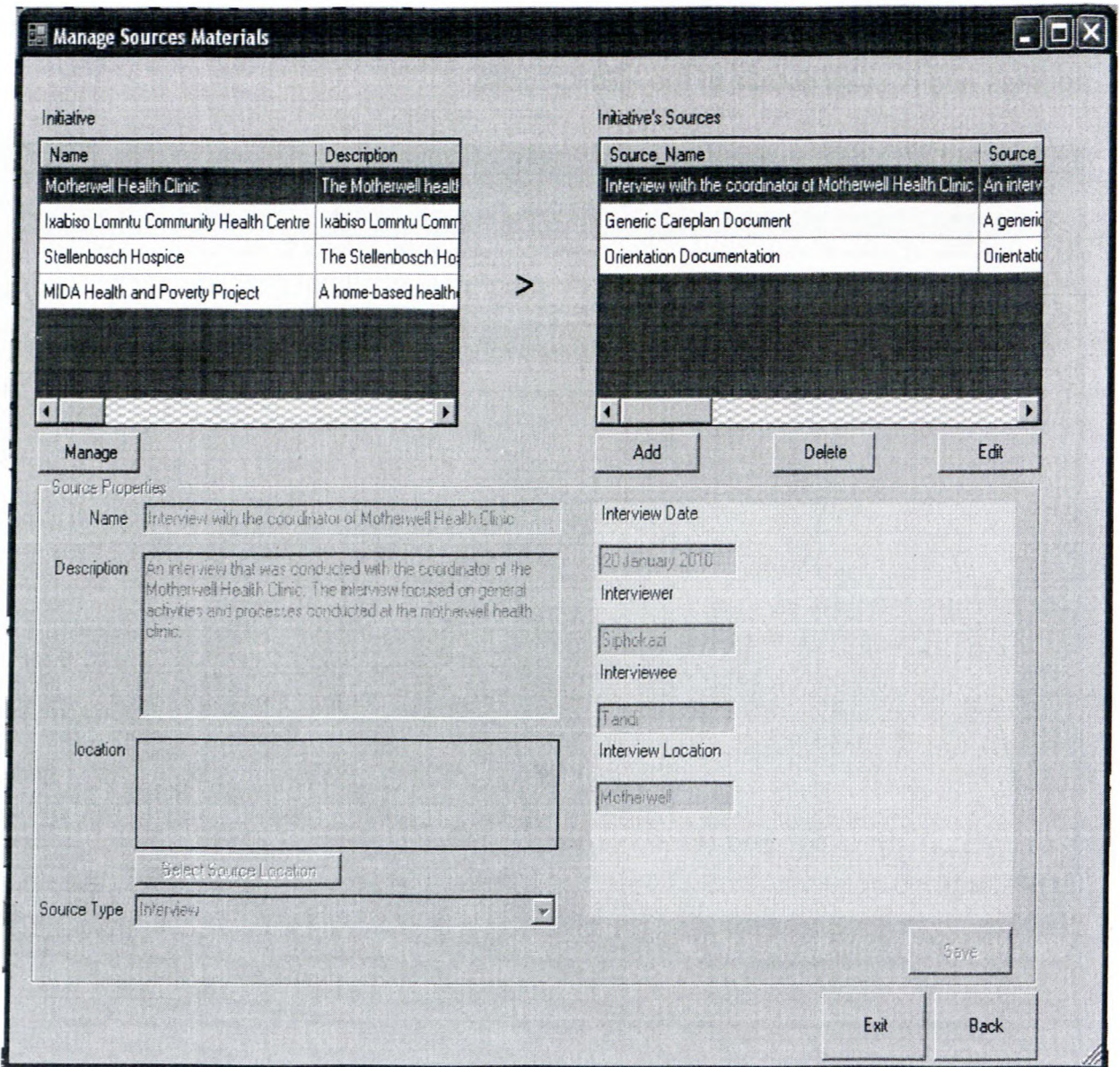
When the user clicks the Manage Initiative button the user interface that allows the user to add new initiative and edit or delete an existing HBHC facility will appear as

shown in Figure 6.2. The user will be allowed to add or edit the name, description, address and contact details of the HBHC facility.



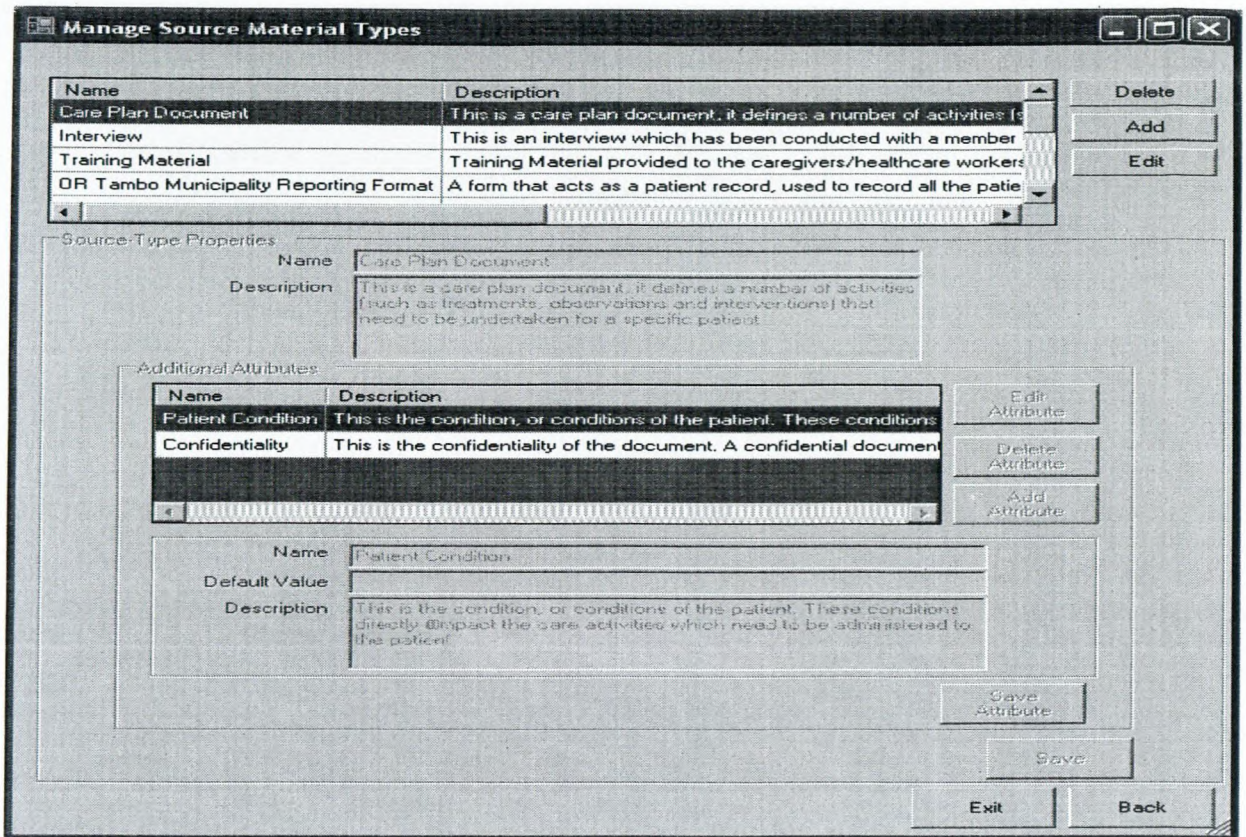
**Figure D.2. Manage initiative screen**

When the user clicks the Manage sources button the screen for capturing and editing the sources appears (see Figure 6.3.). The user can add, edit or delete sources.



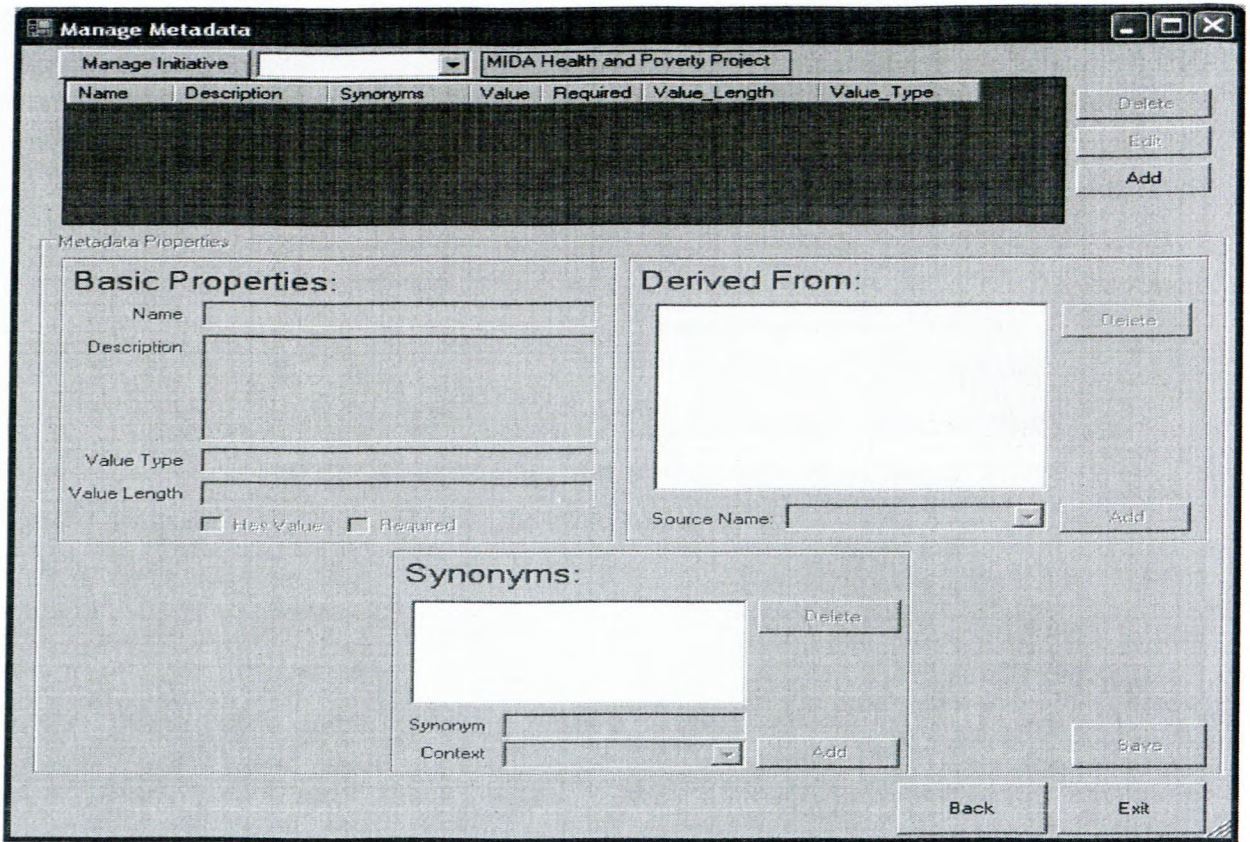
**Figure D 3. Manage Source screen**

On the Manage Source Material Types screen (**Figure 6.4.**) the user will be able to enter the name of the source, its description and additional attributes. The user can add new source types, edit or delete existing source types. The source can have several attributes. The user can also select a default value.



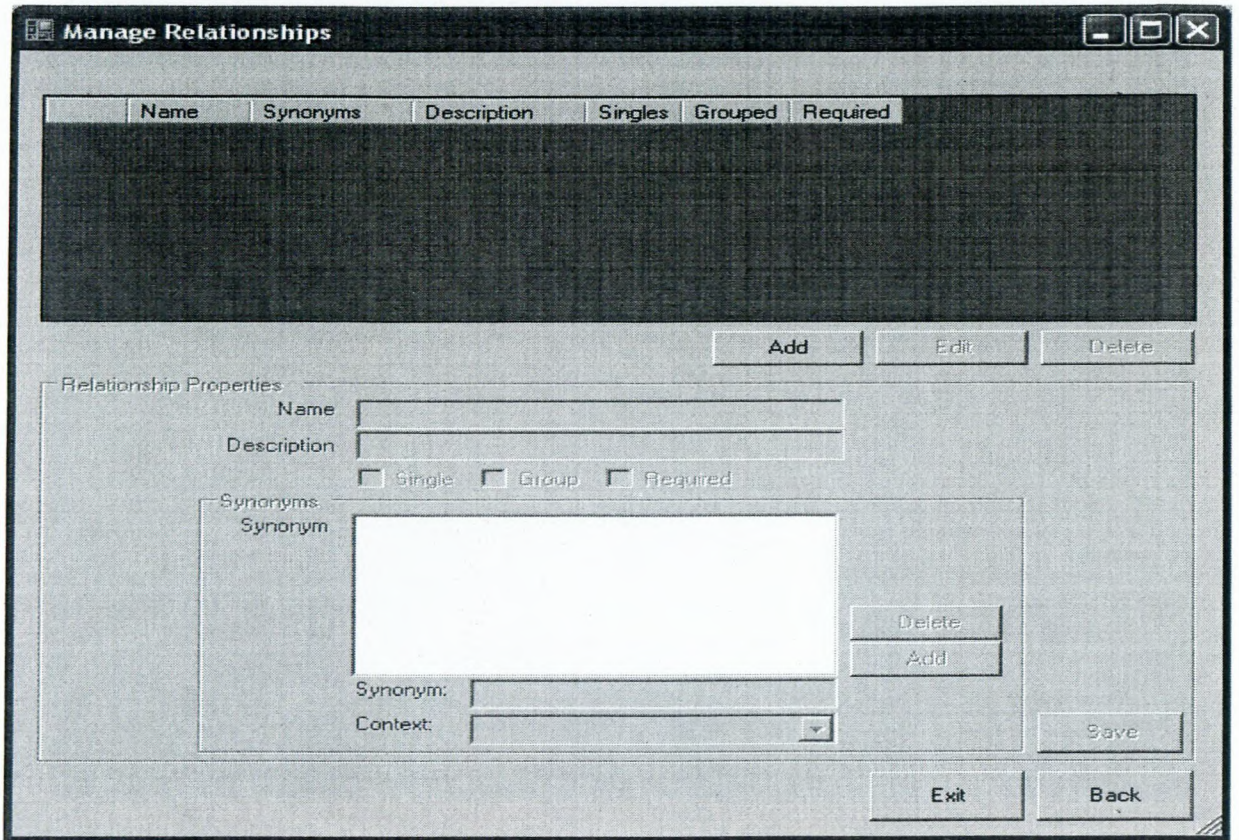
**Figure D 4. Manage Source Material Types screen**

When the user clicks the Manage metadata from the main screen, the Manage Metadata user interface will appear as shown in Figure 6.5. The name of the facility for which the metadata is for will be shown on top of the screen. The user can click the dropdown list and select another HBHC facility if the one shown is not the one they wish to capture, edit or delete the metadata for. The name, description, value, length, type and whether the data element is required or not will be shown in the b. The user can add, edit or delete this information. There is also an option to state the source where the data element is derived from and add synonyms for the data element. This is particularly important for caregivers as the names of the data elements used in different communities may differ. A synonym of Surname may be Last name or iFani in Xhosa context. Another example of data elements that may be used the same way yet have different names in different communities is the Household Number which is used in Dutywa as there are no street numbers and names in the village and Physical Address in Kayamandi area.



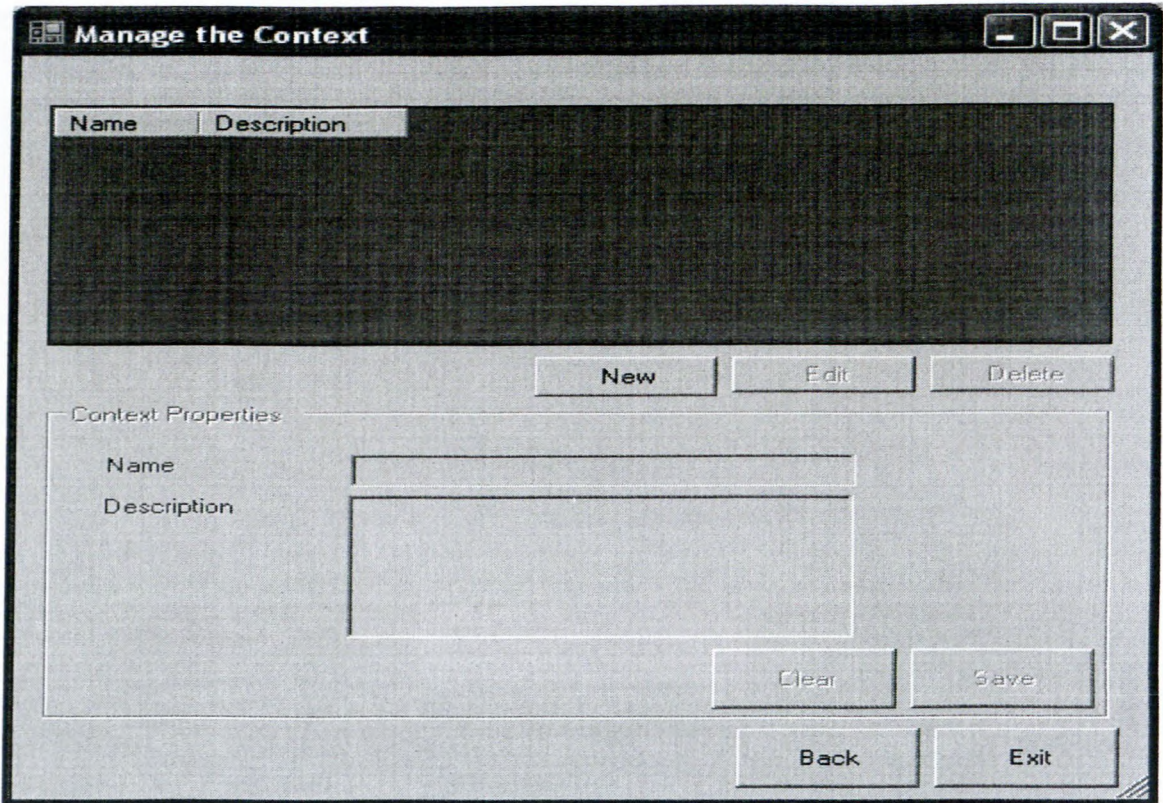
**Figure D.5. Manage Metadata screen**

The user can also add, edit or delete relationships between data elements. The Manage Relationship screen (**Figure 6.6.**) shows how data elements relate to each other, whether the data element is grouped with another to form a new data element or the data element is a combination of other two data elements. An example of such a data element would be a full name. A full name is a combination of two data elements First Name and Surname which maybe be stored separately in other repositories.



**Figure D 6. Manage Relationships screen**

The Manage context screen (Figure 6.7.) shows the name and the description of contexts where the data elements are used. The user can add, edit and delete these.



**Figure D 7. Manage the Context screen**

### **Challenges of using the metadata repository**

Using the metadata repository for capturing caregivers IK and data elements was a challenging task. One of the challenges for the researcher was the tool had many errors and often crashed when the researcher captured the data. The researcher had to consult the developer to ensure all bugs were fixed and the repository was usable.

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