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The illness origin, progression and response among patients receiving home based care in Bushbuckridge South Africa

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THE ILLNESS ORIGIN, PROGRESSION AND RESPONSE AMONG PATIENTS RECEIVING HOME BASED CARE IN BUSHBUCKRIDGE SOUTH AFRICA

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511695

A RESEARCH REPORT SUBMITTED TO THE SCHOOL OF PUBLIC HEALTH, UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG, IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF PUBLIC HEALTH

September 2013

DECLARATION

I, Jennifer Hove hereby declare that this research report is my own unaided work. It is being submitted for the degree of Masters in Public Health, Faculty of Health Sciences in the School of Public Health at the University of Witwatersrand, Johannesburg. It has not been submitted entirely or partially for any degree or examination at this or any other University.

Signature J.H (consider it signed)

Date 25/09/2013

DEDICATION

I wish to dedicate this research report to my husband, my two daughters (Ruvimbo & Zoe) for the love and support they gave me during my three-year study period at the University of Witwatersrand in Johannesburg, South Africa.

Abstract

Introduction: In recent years, the need for health care has grown tremendously catching the health system unprepared. Home based care (HBC) programmes play a vital role as an overwhelmed public health care system fails to cope with the demand of human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS). Patients in rural South Africa face social and economic hardships as a result of tuberculosis (TB), HIV/AIDS and other chronic conditions due to limitations in health care access, shortages of health care workers and established inequities. The provision of home care by community care workers (CCW) has the potential to change the illness experience of people in rural communities when tailored to their specific needs. The aim of this study was to explore experiences of patients receiving HBC in a rural area of South Africa.

Specific objectives: To describe perspectives of men and women receiving HBC on the origin and progression of their illness, to explore their perceived care-seeking behaviour in response to their illness experience, and to explore their perceived role of home caring in the context of home-based care in Bushbuckridge during the period of April to July 2010. **Study design:** Explorative in-depth qualitative study. **Study site**: Bushbuckridge, Mpumalanga Province, South Africa. **Study population and Sample:** 32 patients receiving home care in nine HBC organizations were purposefully selected. Excluded were patients too sick to be interviewed, below 18 years and without a primary care giver. **Data Collection:** Individual in-depth interviews were conducted to explore the following themes: personal experiences of being ill, services being provided by HBC, relationship between CCW, PCG and patient, experiences with CCW in regard to care they provide, challenges experienced and feelings about nature of care being provided.

Data Analysis: Inductive codes were developed after reading the data to identify issues raised by participants. Inductive codes allowed for data to ‘speak for itself’. This process involved reading and re-reading the data to identify explicit codes. Interviews were broadly coded and framed within Suchman’s conceptual framework of illness experience. **Results**: The results shed light on the way in which illness was understood. Belief systems directly affect how participants understood symptoms and responded to illness. Participants’ experiences of illness was shaped by several needs, which included physical, medical, social, financial, physiological and emotional needs. **Conclusion**: In developing HBC programmes, it is important to consider the perceived needs of people with chronic illness in a rural community of Bushbuckridge, so that interventions can be tailored accordingly. The results of this study may help guide HBC programmes that uphold quality of care improvement and people-centred engagement in health care within rural communities.

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Key Words

Community Care Worker (CCW) is the individual responsible for provision of services or care to the patient in the home within the community.

Primary Care Giver (PCG) is the individual tasked with the day in and day out task of taking care of the patient in the home, usually a relative.

Patient is the recipient of care, and for the purpose of this study our patients are HIV/AIDS, TB, stroke, hypertension, diabetes, cancer and asthma.

Home based care (HBC) – the provision of health services by formal and informal caregivers in the home, in order to promote, restore and a person's maximum level of comfort, function and health including care towards dignified death.

Illness is the person's experience of disease including both behavioural changes and feelings of being sick, either of which are related to the person's social context (perception, behaviour & experience).

Disease is an undesirable physiological state, process or conditions in which the internal functioning of the body as a biological organism is impaired.

Sickness is sociological concept and can be defined as a social condition that is associated with people who are deemed by others to be ill.

Chapter One

1.0 Introduction

There is an increasing burden of disease in low and middle income countries, driven by tuberculosis (TB), human immunodeficiency virus (HIV) and acquired immune-deficiency syndrome (AIDS), as well as non-communicable diseases such as cardiovascular diseases and diabetes (1). South Africa is also undergoing a health transition that is characterized by a quadruple burden of communicable, a rise in non-communicable, perinatal and maternal, and injury-related disorders (2). With approximately six million infected with HIV, South Africa is burdened with the largest infected population for any country (3). South Africa, being a middle income country has one of the highest levels of income inequality in the world (4). Even though post-apartheid policies have served to increase health spending in rural areas, most rural residents still bear the largest burden of illness (5).

The rise in disease throughout the country has created a burden on already under-resourced and weak public health care facilities (5). Health care services have become increasingly unable to cope with the needs of ill patients, particularly in rural areas, where patients have limited resources to access regular health care (1). Primary health care has adapted little to respond effectively to this growing demand for continuous and long-term care, as it remains inadequately funded and under-resourced (6-7). As a result, much of the burden of caring for those infected with HIV/AIDS and suffering from other chronic illnesses falls onto households and communities (8). Home based care (HBC) is seen to provide a continuum of care and support to patients with a variety of health conditions (4-5). Patients with chronic illness are living longer and patients with acute conditions are discharged from hospitals early, increasing the need for and often less costly care in the home (9-10). This has influenced a paradigm shift in medical care delivery from hospital-based care to HBC.

In South Africa, HBC for the chronically ill has been increasing over the years. This is especially important in rural areas of South Africa, where patients have many barriers that include geographical, financial, access to information and social cultural attitudes related to gender (1). Hospital staff attitudes and lack of responsiveness by the health system (emergency transport, lack of trust and waiting times) make patients in rural areas less likely to use public health services even though primary health care is free (4, 8). Notwithstanding these health system constraints, it is fitting to note that the illness experience during disease progression tends to vary from one population to another, and from patient to patient (11). These variations will very likely affect the way the chronically-ill access and use HBC services. Therefore, understanding patients' experiences of HBC may serve to inform opportunities to strengthen the health system in general.

1.1.0 Background

The South African government in its 2003 Operational Plan for Comprehensive HIV/AIDS Care, Management and Treatment, stated one of its major objectives as providing adequate community based treatment, care and support services for people living with HIV/AIDS before the end of the decade (12). Several HBC programmes for HIV/AIDS have since received government funds and training for their community health workers (13-14). However, the functional status of these organizations is poorly documented. In 2010, a situational analysis was carried out for the primary study to identify all HBC organizations in Bushbuckridge. Findings from the situational analysis identified 37 HBC organizations, of which 59% were funded by either government or private donors. A total of 41% HBC organizations were not funded due to a variety of reasons. For example, some organizations were just starting off and not yet registered as Non Profit Organizations (15). Most likely, these funding disparities affect service delivery, and therefore patients' experiences of care provided.

Each organization provided care to the elderly, chronically ill, people with HIV/AIDS, disabled, mental problems and TB, but there were also two organizations that predominantly provided care to orphans and vulnerable children (OVCs). For these organizations, and as noted generally in the literature, HBC services vary depending on the patients' needs and tend to include : washing clothes, bathing clients, cleaning the house, health education, dressing wounds, transporting clients to the clinic or hospital, cooking for them, providing them with comfort, counselling and emotional support (15-17). According to the situational analysis done in Bushbuckridge (BBR) in 2010, each organization was required to submit a report to the department of health (DoH) monthly (15).The report required the number of registered patients, specifically referring the number of patients the organization actually brought forth to be diagnosed, so that they could be cared for in the home appropriately. This was to encourage HBC organizations to refer their patients to the clinics or hospital. The CCWs were encouraged by their organizations to see five patients a day (15). However, there was no indication as to how many patients they were expected to register, or the type of care that was needed by each patient. Moreover, some patients were referred to HBC organizations by clinics or hospitals; others were identified by CCWs during their home visits, while others were referred by the community members. All patients referred to HBC organizations were to be registered, and patients who were not registered were not accounted for in the records.

HBC organizations are not regarded as part of the formal health system, even though they contribute towards the health care of patients (14). The result has been failure on the part of the health system to adequately monitor, support or understand their work, hence the rise and fall of many organizations (15-16). This lack of proper monitoring systems renders HBC services as non-efficient in the eyes of resource managers, funders, and policy makers (15).There is a need to better understand in an evidence based manner the structure and capacity of HBC to strengthen the system prior to its integration into the health system. The integration of HBC

organizations into the health system is vital, not only in terms of their impact in relieving the health burden on medical institutions, but also in terms of their ability to provide support and contribute to prevention efforts, improvement of the quality of care, recovery and quality of life (16). HBC is faced with the challenge that public resources are limited and there is competition for resources. Therefore, it is plausible that there is need to prioritize funding and ration funding allocation to most deprived areas. For this reason, the little funds used in HBC should be used efficiently to ensure big returns for limited resources. However, services have to be tailored in a way that ensures the biggest impact by addressing the gaps observed through the eyes of the patient, so as to guarantee satisfaction with care or high perceived quality of care. The negative consequences of failure to sustain HBC programmes is most felt by the recipient of care, the patient (14). Hence, the aim of this study is to explore the experiences of patients receiving HBC in a rural area of South Africa using in-depth qualitative research. We apply Suchman's 1965 conceptual framework of illness experience to guide the analysis and interpretation of data for this study.

1.1.1 Problem Statement

In order to establish the extent of met and unmet health needs among patients receiving home based care, so as to map out compatibility between care received and symptoms experienced, it is imperative that we track illness experiences of these home-based patients. Current trends in HIV/AIDS care and other long term illnesses in South Africa include de-hospitalization and outpatient treatment (18-19). This may place patients at increased risk of having unmet needs of assistance with activities of daily living demands. Knowing the met and unmet needs, one could better inform the agenda for HBC services, so that intervention can be tailored to the health needs of patients. Information on patients' experience could help in developing and

strengthening HBC programs within local communities, particularly with regards to improvement of care services and quality of life.

1.1.2 Justification of the study

In recent years, the need for health care has grown tremendously, arguably catching the health system unprepared. HBC programmes play a vital role as an overwhelmed public health care system fails to cope with the demand of HIV/AIDS and chronically ill patients. Patients in rural South Africa face social and economic hardships as a result of TB, HIV/AIDS and other chronic conditions due to limitations to health care access, shortages of health care workers and established inequities. There is a need to better understand the structure and capacity of home based care, so as to strengthen the broader health care system in an evidence-based manner, and improve the quality of care at home. Strengths, weaknesses and possible improvements of home based care programmes can be deeply understood when examined through the lens of illness experience described by recipients of care.

1.2. 0 Literature Review

1.2.1 Patient illness experience in rural South Africa

Chronic illnesses including TB and HIV/AIDS disproportionately affect poor and marginalized communities (1). Early diagnosis and medical intervention can slow disease progression and improve the quality of life for patients. However, many patients have difficulties in maintaining adequate health care, even when they are diagnosed early (20). Social and cultural conditions such as living conditions may affect engagement with health care and adherence to treatment (1, 5-6). The way in which illness is understood and experienced, either through personal significance, social environment, cultural category and biological disorder or a combination of these, informs the kind of treatment that is sought to heal the illness (21).

In rural communities, the first step of help seeking behaviour include consultation with family members, friends and neighbours (21). Hence the decision to act upon symptoms is not necessarily taken by the individual experiencing the symptoms, but is based upon advice from within the social network. Therefore, an ill individual may decide to seek help from either traditional, allopathic medicine or a combination thereof. However, there is a wide variation in the decision where and when to seek help. For some individuals, it's an immediate decision upon the appearance or onset of symptoms, whereas others go through a period of widespread consultation and approval by significant others in their social networks (21).

According to the health belief model (HBM), firstly, an individual will take a health related action, if he/she feels a negative health condition can be avoided. Secondly, if the person has a positive expectation that taking a recommended action, a negative health condition can be avoided (22). Lastly, if the person believes that he/she can successfully take recommended health action. The HBM model addresses four major constructs which are perceived benefits, perceived barriers, perceived susceptibility of the disease, and perceived severity of the disease. In addition, there are modifying factors that affect behaviour which may include age, sex, socio-economic status, health professionals, incentives and knowledge (22).

Furthermore, response to illness is influenced by the individual, disease, availability and accessibility of health services (23). Table 1 shows a visual summary of health seeking behaviour determinants. Dependent on these determinants and their interaction, health seeking behaviour becomes a complex outcome of various factors operating at individual, family and community level (23-24). The final decision to seek help is often influenced by cultural expectations, beliefs and values. Research has shown that the perception that illness is not serious enough to warrant medical care is the commonest reason for delayed care (1, 25). Distance, unaffordable transport, anticipation of disrespectful providers and belief that care would be ineffective are more prominent barriers in rural areas (1, 26). However, within the

same geographical settings, different patient cope differently with the illness. These in turn shape the individual's experience of their illness.

Table 1: Determinants of health seeking behaviour

Determinant	Empirical Measure	Examples
Cultural	Values linked to pain, Status of women	Elements of patriarchy
Social	Age and sex	
Socio economic	Household resources	Education level Maternal occupation Marital status Economic status
Economic	Costs of care	Treatment Travel Time
Type and severity of illness		
Geographical	Distance and physical access	
Organizational	Perceived quality	Standard of drugs Standard of equipment

	Competence of staff Attitudes of staff Interpersonal process

(Adapted from Mackian S *et al* 2004)

Many studies have explored the challenges faced by people living with HIV/AIDS (1, 16, 20, 27). While these studies are robust and generalizable, current literature is increasingly recognizing the importance of acknowledging different contexts, and that locally-relevant research should be used to study patterns of diseases and health care, so that local solutions can be found. Furthermore each culture and social group and sometimes each family have its own unique way of representing distress. Cultural variables such as perceptions of illness are important in understanding illness experiences, which are not easily described using quantitative methodology and have not been adequately studied in rural South Africa (21). Specifically, there is inadequate insight to patient's perceptions of illness regarding the care they receive.

Furthermore, there is growing need in providing information to support patients' participation in choosing treatments and other decision-making processes (5). Patients' participation is important in shaping health policy and patient-centred care. Describing the illness story from the patient's perspective could increase caregivers' understanding of patients'' experiences related to living with an illness for HBC programmes, health professionals and others, thus informing decision-making processes. With limited information available, describing the illness story, life with the disease, before and after diagnosis, and illuminated from the patient's perspective, are all vital for improved quality of care (4-5).

1.2.2 Conceptual Framework

The conceptual framework used in this research was developed by Suchman in 1965 (28). The illness experience is described and analysed in five stages, namely symptom experience, assumption of the sick role, medical care contact, dependent patient role and recovery or rehabilitation (28). Each stage is characterized by certain decisions, behaviours and end points. The model has been widely used to explore patients' experiences with a wide variety of health conditions (29-30). The symptom experience stage involves physical stimuli through which the individual experience some pain, discomfort or change of appearance. It also involves a cognitive aspect where an individual interprets and derives meaning from experiencing the symptoms. The last aspect of this stage is the emotional responses of fear or anxiety derived from both physical experience and cognitive interpretation (28). In most cases, these symptoms will be recognized and defined in terms of their interference with normal functioning, and not necessarily in medical diagnostic categories. During stage 2 of assumption of the sick role, the patient begins to seek information, guidance and advice from significant others and temporary acceptance of the condition by family and friends. However, in an African context, decision to seek medical care is not merely an individual's, but also a social action which concerns and involves other members of the individual's social circle or unit (21).

In stage 3 of the medical care contact, the patient seeks professional advice rather than advice from lay sources. In some cases, this stage may be prolonged if the patient refuses to accept the initial diagnosis or treatment, and begin a lay search for other sources of alternative medical care in keeping with his or her needs and preconceptions (28). The selection of the source of care will depends on the knowledge, availability and convenience of such services and influences from other people. At this stage, the reasons for delay in seeking professional care can be examined (triggers and barriers).

During stage 4, or the dependent-patient role stage, professional treatment is accepted by the sick person who is now generally perceived as a patient. At any time during this stage, the patient may experience ambivalent feelings and may decide to reject treatment, the caregiver or the illness. The patient has a particular need to be informed and be given emotional support during this stage. Important at this stage is the patient's relationship with the caregivers, as it affects their communication and interaction. In stage 5, the patient relinquishes the sick role (28). In this study, illness origin, progression and response was categorized into common themes and patterns of perceptions of illness with regard to these five dimensions (see table 2).

Suchman's model provides a good conceptual framework for looking at the succession of events in illness experience. However, critical literature on the model suggests that it's limited by its inability to provide means of looking at how patients decide on what sources of care to utilize among those available (30-31). Furthermore, there is no evidence to suggest that this model has been used in African societies, where the traditional system coexists with the western medical system. Therefore, in the analysis of data from this study, both strengths and limitations of this model will be taken into consideration.

Table 2: Illness experience model

Dimension of illness	**Model as described in the literature**	**Model as adapted for this study**
Symptom Experience	Physical symptom experience-discomfort, pain change of appearance Interpretation & meaning of symptoms Emotional response	Physical symptom experienced-discomfort, pain, change of appearance Ways in which symptoms were defined and interpreted.

		Perceived causes of symptoms Emotional response- fear of death or anxiety
Assumption of the sick role	The decision that one is sick, where the patient seeks symptom alleviation information from significant others. Acceptance of the patient status by the patient or family members	Participants' lay consultation from significant others (friend, neighbour, family or community member. Advice from significant others.
Medical care contact	The decision to seek professional medical care. Initial medical diagnosis	What did participants do in response to their symptoms- triggers for seeking professional medical care Participants 's perceived barriers for seeking professional medical care
Dependent patient role	Accepting and following prescribed treatment.	Participants' acceptance of health condition and treatment. Relationship with family members' community and community care workers. Description of social support. Giving up responsibilities due to illness
The recovery or	Patient either withdraws or is dismissed from active medical care.	The patient continues their medication while at home.

rehabilitation stage	The patient can either resume his old role of a health individual or adopt a new role of a healthy chronic invalid	Depending on their situations some patient either resumes their roles of health individual or adapt to new role of a healthy chronic invalid. The provision of home care

1.2.3 Study aims and objectives

The study aimed to explore the illness experience of patients receiving home based care in Bushbuckridge, South Africa within the period of April to July 2010. The objectives were to:

- Describe patients' perspectives on the origins and progression of their illness among adult males and females receiving HBC in Bushbuckridge during the period of April to July 2010.
- Explore perceived care responses to their illness experiences during the period of April to July 2010.
- Explore the perceived role of home caring on people's illness experience in Bushbuckridge during the period of April to July 2010.

Chapter Two

Methodology

2.0 Introduction

This chapter covers study design, background information about the study site, criteria used for sample selection. Data collection, analysis and management are described here under.

2.1. 0 Study Design

This study used secondary data that was collected from a large multi-phase study of HBC in the Bushbuckridge sub-district. The primary study used an explorative in-depth qualitative study design to investigate the quality of health care and support provided by HBC programmes through the CCW and PCG to the recipient of care. The link between the CCW, PCG and patient is shown below on Figure 1. This study used secondary qualitative data analysis from the primary data, focusing on the recipient of care - the patient.

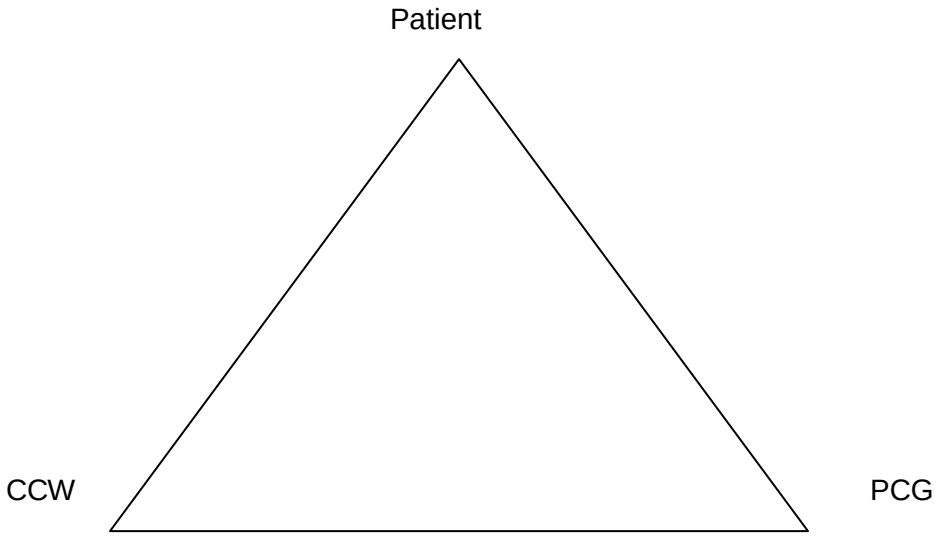


Fig 1: the relationships among CCW, PCG and Patient

2.2.0 Study Site

Bushbuckridge is located in Ehlanzeni District in the Lowveld areas of Mpumalanga province, north-east of South Africa. The rural sub-district is densely-populated with approximately 520,000 people in 34 wards and over 135 villages (32). Infrastructure development and population density across the area are heterogeneous, ranging from fully serviced houses to isolated rural homesteads without water, electricity or sanitation (33). Females represent a considerable majority (almost 54%), a reflection of the impact of the migrant labour(34). Almost all of Bushbuckridge was under the jurisdiction of Lebowa and Gazankulu, former homeland areas prior to 1994. There is a high unemployment rate and limited economic base. Nearly 80 percent of the population is unemployed, and 84 percent of the population earns less than R1,300.00 per household per month (32). Few households have land or livestock sufficient to support livelihoods (34). Poverty remains widespread, and it has been estimated that 60 percent of households receive child support grants (33-34).

2.3.0 Study Population and Sample

The patients receiving home care in nine HBC organizations in Bushbuckridge were purposefully selected based on a set criterion, based on sex, age and diseases. The objective was to obtain a sample that was diversified and represented important subgroups. The CCWs were asked to provide lists of their patients. Patients who satisfied the basic inclusion criteria were selected from the list. The patients were selected in such a way that the sample would cover a range of possible characteristics of interest and perceptions. Participants suffering from HIV/AIDS, TB, stroke, Diabetes and hypertension were interviewed and their ages ranged from 25-86. In total, the sample size consisted of 32 participants. Excluded were patients too sick to be interviewed, below 18 years and without a primary care giver.

2.4.0 Data Collection

Data collection took place in 2010, from April to July. Data were collected through individual semi-structured interviews with the 32 patients receiving care from HBC organizations. An interview guide **(see appendix A)** was developed in English, and questions were translated into Xitsonga, SiSwati and Sotho, which are the most commonly spoken languages in the area. Interview questions revolved around the following topics: personal experiences of being ill, services being provided by HBC, relationship between CCW, PCG and patient, experiences with CCW in regard to care they provide, challenges experienced, feelings about nature of care being provided and suggestions for improvement. Patients were interviewed in the language they preferred. The interviews were conducted at the patients' home and lasted from 40 to 80 minutes.

Interviews were conducted by three research teams comprising two individuals per team. Two teams comprised of a female and male interviewer, and one team had two females. The research teams were trained on how to conduct the interviews. All interviews were recorded on a tape recorder with permission from the patient. Field observation notes were taken to add value to the context of the interviews. The patient received light refreshments after the interviews. This study focused on the analysis of transcripts from the above source study.

2.4.1 Data management and analysis

All recordings were transferred and stored in password protected computers. Audio recordings were transcribed verbatim during and after the actual interviews. Field observation notes were also included in the transcripts. Quality checks were done by independent researchers to ensure quality of data collected and transcribed. Transcripts were de-identified to ensure privacy

and confidentiality and pseudonyms were used. The pages of transcripts ranged from five to ten pages per interview.

Both inductive and deductive codes were developed to analyse the data. No software was used in the analysis of data. Deductive codes were not derived from reading the data, but are those that come from aspects of the research considered during the design cycle, for example topics in the interview guide for patients and conceptual framework (35). Inductive codes were developed after reading the data, identifying issues raised by patients. These codes were identified through reading and re-reading of the data (35-36). Coding stopped at the point of saturation when there was no more new information. Inductive codes allowed for data to 'speak for itself' (35). Valid and useful codes were included in the analysis. Validity or usefulness of the codes was checked by identifying whether a given code was repeated across different interviews in the study, and whether the code was highlighted by participants as an important issue as well as isolated factors since these were potentially very important. Strategies that were used for this study to identify inductive codes include but are not limited to the following; reading for overall content, familiarisation, annotating data and noticing repetition of issues (35, 37). Concepts were clustered together, codes reduced and expanded for interpretation and meaning attributed to patients' articulated experiences. The codes were further developed or grouped into sub-themes and then themes according to how the data is related to the Suchman's conceptual framework. The data were used to create a descriptive analysis of illness experience from the time the illness commenced to the time of the interview. In this part of analysis, sub-themes were generated from the codes, which were grouped under different constructs of the illness experience framework.

2.5.0 Ethics consideration

The primary study was approved by the ethical review committee at the University of Witwatersrand, Johannesburg, (clearance number M090232) and the Department of Health and

Social Development in Mpumalanga **(refer Appendix B)**. An information leaflet with background information about the study was issued to the participants **(refer appendix C).** Written informed consent was obtained from all participants for both interviewing and recordings on the illness experience and care **(refer appendix C)**. Pseudonyms were used for patients interviewed and all the information gathered was kept strictly confidential. This current study was approved by the ethical review committee of the University of Witwatersrand and gave a certificate clearance number M120528 **(refer appendix D).**

Chapter Three

Results

3.0 Introduction

The patient's illness experience is described under the following themes; onset, progression, response, role of home caring and recovery.

3.1.0 Characteristics of participants

Majority of the thirty two patients who participated in the in-depth interviews were HIV/AIDS patients (16), while others were diagnosed with TB, diabetes, hypertension, stroke, swollen legs and asthma at the time of the interviews. All participants were receiving some kind of services from the nine home based care organisations depending on their need and situation. The mean age of participants was 52.3 (range 25 to 82 years), and majority were females (62.5%, N=20). Out of 32 participants interviewed, three were leaving alone, fourteen were receiving a grant personally or through a family member, and three had stopped receiving grants.

Table 3: Participant characteristics

Mean Age	52.3 (range 25-82yrs)
Female	62.5% (N=20)
Diseases	
HIV/AIDS + TB	16
TB only	5
Diabetes	3
Hypertension only	3
Stroke	2
Swollen legs/old age	2

Asthma	1
Grant	
Family member receiving grant at the time of interview	14
Household not on grant at the time of the interview	15
Households stopped receiving grants	3
Patients living alone at the time of interview	3
Patients living with family members	29

3.2.1 Origin and progression of symptoms

More than half the participants reported that they experienced body pain, discomfort and change of appearance. **Table 4** shows some of the self-reported symptoms participants experienced. Majority of participants suffered from headaches, weakness, stomach pains, diarrhoea and poor appetite. Some participants who were not receiving grants and others who were staying alone at the time of the interview reported several symptoms. HIV/AIDS patients found dreadful the nights before ARV initiation. They experienced a lot of pain and various symptoms as one participant reported;

"I had a headache, painful legs and was quivering like if am feeling too much cold, poor appetite and vomiting after taking food. I was feeling pain all over my body and I did not understand what was wrong with me. That's how I started to be sick" [Primrose].

Table 4: Self-reported symptoms experienced by patients during their illness

Problem	Number of patients
Headaches	21
Weakness	17

Coughing	14
Diarrhoea	12
Stomach pains	11
Swollen feet/painful legs	9
Poor appetite	8
Fever	7
Vomiting	6
Weight loss	5
Night sweats	5
Chest pain	4
Bleeding	4
Shortness of breath	3
Itchy rash	3
Anxiety	3
Depression(sadness)	3
Tiredness	3
Insomnia	3
Numbness	3
Dizziness	2
Thirsty	2
Sores	2
Memory loss	1

3.2.2 Interpretation and meaning of symptoms

Responses suggested that participants interpreted and derived various meaning from their illness/symptom experience – the meaning of symptoms. During the early days of their illness, twelve out of sixteen HIV/AIDS participants could not relate the symptoms with the disease they

were suffering, though 4/16 were suspecting they might have HIV. However, as their diseases progressed, their symptoms became abnormal and unbearable. These symptoms were in most cases defined less in clear medically diagnostic categories, but more in terms of their interference with normal social functioning. This was also the case for diabetic and asthmatic participants.

"I had headaches, sometimes my bones are not good and I feel pains, feeling body pain and tiredness especially when am walking or working even a light duty. Then I was asking myself why my body is not the same as before, comparing tasks that I can be able to do in a day"[Rifiliwe]

Meanwhile four out of five TB participants could relate their symptoms with the disease they were diagnosed.

In contrary, all stroke participants suspected that they might have stroke after an attack (symptoms). There was therefore a difference among TB and stroke participants. All stroke participants reported that their symptom affected their daily life. They reported body pain, discomfort, they spoke of moodiness and depression and they mentioned about physical limitations, weakness and social isolation as one commented;

"I am not sure what caused this really. I just woke up one morning to go to the toilet and when I came back I laid a mattress and sat, when I tried to stand up, my legs couldn't move. Immediately I woke the child, who is staying with me and told her to go get her uncles and they came. They tried to lift me up but they didn't succeed and during that time, the saliva was running out from my mouth and I thought that I might have had a stroke" [Betty].

Much of the distress relating to diagnosis for stroke participants was leaving work, cutting down their working hours and also their relationships being put into disarray.

3.2.3 Perceived cause of symptoms

HIV participants (10/16) were not able to identify the cause of their illness because of their beliefs. The most frequent explanation provided for the cause of their symptoms was bewitchment, and others believed it was a sign or a calling to become a traditional healer. The diagnosis of bewitchment deflected participants' focus on what might be the cause of their illness or what they could have done to contract HIV. On the other hand, the diagnosis of bewitchment contributed towards tension among household members, primary care givers and distrust of people suspected in the community. Andrea reported that her family believed she had a calling to become a traditional healer and she also suspected that people were bewitching her as she commented;

"The problem was in my stomach. It was as if I had a stone inside…I continued to get ill and was in and out of hospital. They (family members) ended up saying that I had a calling and should go and be trained as a traditional healer. I went to the traditional healer and as the operation was healing I could still feel the thing…But I would sometimes faint and when I tried to sleep it would be difficult to breath. When I went to bed at 9 p.m. the ancestors in me would rise up. Even at 12 a.m. and 3 a.m. I thought that maybe some people were bewitching me and sending evil things in my room" [Andrea].

After the diagnosis of HIV, some participants blamed themselves for their illness, while others attributed the cause of their illness to the spouses or partners. Despite diagnosis, some of the participants in the study believed that they were bewitched. Women in the study except one blamed their partners as the cause of their illness as one female participant accounted;

"The man who infected me with this disease is staying in (name of place).We were staying together in (name of place) in (year). But now he passed away in (month) of this year. But he

(partner) was calling me and I was no longer interested in him since I had found out that I am suffering from this disease (HIV)" [Primrose].

However, for the other 16 participants who were diagnosed with TB, diabetes, hypertension, stroke and asthma, they did not know what was the cause of their symptoms. They attributed their ill health to natural causes that only God could explain, they saw their symptoms as an indicative of an illness, though some (4/16) also believed they have been bewitched or poisoned.

3.2.4 Anxiety Experience

In addition to physical body pains, some participants described a downward spiral of sadness and hopelessness as a result of their deteriorating health conditions. These participants were in denial and disbelief, as a result delayed seeking and securing treatment. Most participants who were in denial reported stress related symptoms including insomnia, headaches and at times reported high blood pressure. The anxiety experience was often the reason participants sought health care. Out of 32 participants, 25 were more concerned with the appearance of symptoms, Beulah participant reported:

"I started coughing a lot. I then decided to go to the clinic in (months) and they gave me a collection kit that I may supply sputum. I decided to test for HIV/AIDS because I understand TB goes together in most cases with HIV/AIDS, so that they can be able to DOT me… [Eunah]

Other participants were afraid of death; the narratives testified the expectation of death as another participant described;

"I stayed there (hospital) for a while. But what was really stressing and making me lose more weight the most was the fact that many of the people I was with died. I refused to let them put a

nappy on me and told them I could walk by myself be leaning on the walls. They said that I was the only one in there that was a little better. But I wasn't eating anything" [Naboth]

3.3.1 Lay consultation with Family

Lay consultation with Family

Most participants believed that they were sick and needed care. Approximately 72% (23/32) reported discussing their symptoms with someone before seeking health care. Most of the discussions were either with a relative as in spouse, child, mother or father or with a community care worker. Advice from significant others influenced participants' choice of health care. Interestingly, most participants (21/32) followed advice and recommendations of their discussions whether it was to see a traditional healer, go to a clinic/hospital, pharmacy or self-medicate as was reported by Nation:

"During my illness as I had only one sore which multiplied when scratched, I asked people. Then talked to my parents telling them that when asking people from around about my symptoms they told me that I had herpes zoster…… Then my parents gave me the little they had for me to seek help at the traditional healer" [Nation]

However, other participants (3/32) were coerced by significant others to accept their advice on the use of health care. Participants' initial responses to their symptoms were informed in part by their social environment, especially family members who sometimes encouraged them to visit traditional healers as Andrea reported:

"I didn't want to go to the traditional healers but my father forced me because I was always getting ill" [Andrea]

According to the interviews, participants (6/32) were confident to make the decision that they need health care.

Discussion of one's symptoms with significant others varied with disease, sex and age. Participants who were suffering from diseases such as hypertension, diabetes and TB were much more likely to have discussed their symptoms compared to HIV/AIDS participants. Half of HIV/AIDs participants discussed their symptoms prior to the seeking of medical treatment. However, living in rural communities, it was not easy to hide their HIV status, particularly as their disease progressed. Many female participants discussed their symptoms with family members, 17 out of 20 compared to six out twelve men. Younger participants (from 25 to 35 years) discussed better their symptoms with their family members or friends.

3.3.2 Lay consultation with CCWs

Analysis of this stage in the illness experience highlights in general the support and contribution of primary care givers and CCWs. CCWs appeared to succeed in providing the necessary support and guidance towards professional medical care.

"I was sleeping on the bed when she (CCW) came. ….. I told her that I had fever and didn't have much of an appetite and that I had constant headaches. She asked me if I had gone to the clinic to get tested, I said no. I couldn't walk anymore. They hired a car for me and I went with her (CCW) to…" [Naomi]

According to reports from most participants, the discussions were largely successful in providing the individuals experiencing symptoms with vital information, support and guiding them into professional medical care.

"In the beginning when I started to be sick I didn't know what was wrong with me …and I was advised to go for VCT-the results were positive." [Beulah]

3.4.1 Sources of health care

The most frequently used source of health care was the public sector, followed by private sector, traditional/ spiritual healers and self-care provided by participants themselves or family or friends. The initial response to illness for participants prior to diagnosis was to visit the public sector (hospital or clinic) 18/32, followed private sector (7/32) while other participants thought of contacting traditional healers (5/32), two decided to visit a church for health care. Participants' beliefs concerning their ill health and perceived causation influenced the decision to choose either allopathic or traditional sector. Hence treatment was chosen on the basis of beliefs, convenience or availability of treatment options as another participant commented;

"When I tried standing up it was as if something was pulling me down. I tried going to traditional healers and they said I was bewitched" [Lawrence]

3.4.2 Medical Pluralism

As their illness progressed, participants switched from one source of health care to another. Meanwhile 15/32 participants used both allopathic and traditional sectors at some point during their illness. The most frequently mentioned reasons for participants to simultaneously utilize both forms of medicine were lack of improvement and recurrence of symptoms after treatment, and this was most common among HIV/AIDS participants, as another participant stated below;

"It had stopped (pain after operation). I was feeling better. Before I couldn't touch this part (point to her stomach). But it started getting worse again with this ancestors business. It got worse until I refused to be operated for the second time in (year), until I went to the traditional and then to the clinic. After coming back from being trained as a traditional healer I decided to go to the clinic because no matter how much I ate I wasn't gaining weight" [Andrea].

This highlighted the way in which some participants in the study sought out different health care in line with their experience of illness. The fact that one may continue to be ill and lose weight

despite getting help from traditional healers motivated the participant above to try an alternative health care source- the clinic.

3.4.3 The decision to seek allopathic medicine

The point at which an individual decides that a series of body discomforts become worthy of professional care depends on how they perceive their symptoms. That is, the more seriously an illness was perceived or the more severe the symptoms, the more likely the individual would seek professional care. This was evident mostly in all stroke participants. Immediate decisions were made promptly after an attack. In cases where illness was considered less serious or first symptoms less severe, the less likely participants were to visit the clinic or hospital. In such cases participants would opt for other alternative self-medication or visit traditional healers; this was common among HIV/AIDS and TB participants. However, as their illness progressed, participants' resorted to allopathic medicine. The use of traditional care declined over time. However, for some participants (9/32), allopathic medicine was sought as the last resort after traditional medicine were perceived to have failed to provide effective treatment, as another participant narrated;

"What I came across is that I was not eating. If they cooked pap I was irritated and also with the meat. I was irritated with every food I could see. Then I made the decision that I have to see the traditional doctors. In (year), I saw that I was not getting well from traditional healers, and then I made my decision to do blood test because I had done almost everything but nothing could help. I learnt that I was HIV positive in (year)" [Edina].

Meanwhile 5/32 participants continued to use different sources of health care simultaneously.

3.4.4 Barriers to allopathic medicine

Lack of money for food and transport

For some participants, although they received help from hospitals or clinics, they had challenges that included lack of money, food and transport. Most participants (21/ 32) complained that they needed food when they take medication. Some of the pills needed to be taken with food. Others ended up stopping to take their pill because they didn't have food at home.

"…we don't have any food and I didn't take any pills" [Ellen].

"No, I don't have problems with the one taking care of me at home, the clinic or the home based organization…..However my only challenge is I have no food in the house"[Daniel].

Participants attributed the extreme poverty affecting their household to unemployment as most of the participants lost their jobs due to illness. Some patients who were self-employed could not continue with their work due to deteriorating health conditions. According to their reports, poverty led to poor health as most patients were unable to access their treatment on time and obtain the needed nourishment.

Long distances

Many participants had challenges of travelling to health care centres as most of the clinics and hospitals were far from where they live. Long distances presented as one of the greatest stressors, and this was exacerbated by the participants' general lack of money for transport. Some participants, therefore, were left with limited choice but to walk. Participants suggested for decentralization of ARV clinics as one participant commented:

"…I had challenges with walking to the clinic because it was far. But the main challenges were getting my ARVs at Bushbuckridge hospital. Even now I have to leave at 5:00 in the morning to queue at the clinic. Maybe if they could give ARVs to our nearest clinic I think it would be better for us" [Beulah]

Challenges with service providers

Despite the problem of long distance, participants experienced various problems with public clinics and hospitals. Some patients stated that they visited the clinics more than three times but couldn't get their test results;

"I went back and asked for the results and they told me they could not find them" [Lizzie]

Moreover, others were sent back home by clinicians stating that they were not sick or due to unavailability of staff. Sometimes they failed to get their medication due to the unavailability of drugs at clinics or hospitals.

3.5.1 Acceptance of allopathic medicine and health status

Most (26/32) participants described how their symptoms became better after they had visited the clinic or hospital and got some medication. Overwhelmingly, most participants ended up accepting allopathic medicine as their illness progressed. They expressed favourable attitudes towards the services they get at the hospitals and clinics as their conditions improved as one put it;

"However, I had been taught about side effects so we were coping well…..As I continued taking this treatment…. They comfort us (clinicians) and just the other day they told us that they are in the process of coming with an injection instead of pill that will last for about six months, things like that" [Abigail]

Relief of symptoms and effectiveness of treatment appeared to influence the decision to accept allopathic medicine. Participants described managing their life better after visiting the hospital or clinic.

Accepting a positive HIV status was not easy for most infected individuals in this study, despite getting helpful advice from CCW, but they ended up accepting for the sake of their own health. Some participants found it hard to accept a sick role and others struggled to turn their responsibilities to their support system. The restrictions imposed on activities by the illness were largely those that require the performance to work or do household tasks. The reluctance of patients to relinquish their responsibilities was seen through most participants.

"Sometimes you find that there is a swelling on my leg with veins popping out of them. Sometimes they even change colour and became blue. How can I work like this? Which factory can hire me to work for them like this? It's not good. Even now that am sitting here I feel like I am not because other people are busy working" [Naboth]

3.5.2 Influence by Home based care

Participants (23/32) appreciated the services and support provided by CCWs from home based care organizations. Participants put their confidence in CCWs and they were influenced a great deal by inspiring feelings of trust and security. Most patients reported that the CCWs encouraged and supported them to visit the hospital and adhere to treatment making them feel confident and secure. They recognized that the CCWs tried their best and made an effort to be of help to them.

"I was sleeping on the bed when she (CCW) came. She asked me how I was feeling and I told her that I had fever and I didn't have appetite and that I had constant headaches. She asked me I had gone to the clinic to get tested and I said no. I couldn't walk anymore. They hired a car and I went with the CCW… and agreed to be tested. I had my child with me there, so they checked her and found out that she also had this disease" [Naomi]

The support by CCWs improved the emotional health of most but especially HIV/AIDS patients, as they felt less isolated or discriminated, and more accepting of their situations. However, not all participants were fortunate to have supportive PCGs, but the home based care programme had made positive changes in the participant family relationships. Most importantly, the support and awareness implemented through home based care programme caused many participants especially people living HIV/AIDS to see themselves differently. As another patient said;

"You know when you are sick people discriminate and label you, they talk a lot of things about me, especially my relatives…. They call me names, criticize me about my legs……but she (CCW) is good, she even cleans and washes my clothes" [Lee].

Many participants (23/32) interviewed appeared to be satisfied with the level of care they receive from home based care programmes as one commented;

"They (CCWs) support, love and are able to buy me what I want… I receive good care. I really appreciate the care they give me these people from Ebenezer (HBC). I wish they can continue doing well so that I can be better as well as others" [Sara].

"My relationship with her is that she (CCW) has helped me a lot. If it was not her I don't know maybe I would be dead. She really helped me and I am thankful to her" [Naomi-HIV patient]

Despite challenges faced by participants, they displayed complete acceptance to the care they received. 5/32 participants in the study said that they regularly received food from their CCWs during their home visits. In relation to their specific illness and its treatment, most of the participants felt that both their primary care giver and the community care worker were able to help them a lot except a few (9/ 32) as another commented;

"They (CCWS) don't help us much, in fact they do not do anything" [Senzo]

3.5.3 Other social concerns

Participants were concerned about the welfare of their children especially paying for their children's school fees, and most participants interviewed repeated this. However, even those who were getting some grants, it was difficult to meet all their financial needs as the amount granted was far too low to cover even basic commodities and hospital trips. As one participant put it;

"My problem is that I am staying with my child and we are starving. ……..The only child support grant that am receiving could not cover all our needs because we have to eat enough nutrition like fruits and vegetables but because am unemployed and not receiving disability grant, it is difficult to get all those food"[Primrose].

Despite CCWs' visits to participants who were staying alone or had poor social networks, this group had many challenges compared to those who were staying with their relatives or family. Three participants were staying alone during the time of the interviews. This indicated the importance of the role played by the patient's family during illness. Some of the challenges included not having anyone to talk to or confide in, and no one to help with household duties when in pain.

However, a few reported that their social relationships were affected, most women separated with their partners due to illness.

"I was married there and suddenly after the birth of my second born child we started to fight….. My condition worsened while I was here…..I found out that he had a girlfriend and was not treating me well and I couldn't handle the stress so I came back home" [Beulah]

3.6 Recovery or rehabilitation

At the time of the interview, 8/32 participants reported that they were feeling completely well though they continued to take their medication, 22/32 improved, and 2/32 described their condition as worse. 15/32 participants had resumed their usual activities, whereas 7/32 were completely limited. Despite of getting help from the CCWs and PCGs, half of the participants were able to take care of themselves (bathing, washing and cooking).

"At home I can do everything because I am still strong. There is nothing that I am failing to do. At hospital they help with the treatment I am taking it. I am working by myself and you can see that there is no problem; I am even selling the traditional beer on my own. But the problem is this thing I have inside" [Edinah].

Stroke participants were confined to bed for most of the time. The participants described ways in which stroke affected their everyday life; impact on their ability to leave the house, getting around their neighbourhood, doing housework, and impact on the way they talk with and relate to others.

Participants who completed their treatment and adhered to their medication reported better outcomes. All TB participants in the study reported that their treatment was successful as Daniel commented;

It started when I would cough and sweat a lot while asleep. I then decided to go to the clinic where I was given a specimen collection kit so that I could collect my sputum….. I was staying at home; I would have a date booked for collecting my tablets until I completed the dose…. At least I do not cough or sweat anymore [Daniel].

CHAPTER FOUR

4.0 DISCUSSION

4.1 Introduction

The aim of this project was to explore the illness experience of patients receiving home based care in a poor, rural population of Bushbuckridge. The results of this study provide valuable information in the way symptoms are perceived evaluated and acted upon by individuals who recognize pain and discomfort, seen through the lens of home based care programmes in a rural area, with a particular reference to the Bushbuckridge community. In this chapter, we firstly highlight the results from the analysis, starting with the main study findings. Secondly, we compare the study findings with existing knowledge from previous studies. The themes are discussed under stages of Suchman's framework, namely; symptoms experience, assumption of sick role, medical care contact, patient dependent role and recovery or rehabilitation. The role of home caring is also discussed. Lastly, we discuss some of the limitations and strengths of the study.

4.2 Symptom Experience

Patients in this study reported various symptoms, depending on the disease they were suffering from. HIV /AIDS patients reported numerous symptoms that indicated disease progression compared to other patients. Furthermore, symptoms reported differ before ARV initiation for HIV patients and treatment onset for other chronic patients. Multiple symptoms were reported before the onset of treatment. The findings in the current study suggests that despite improved treatment for HIV/AIDS and other chronic ailments in South Africa, patients living in rural areas continue to experience high levels of physical and psychological symptoms (4, 38).The study

results revealed that socioeconomic factors such as lower education levels, unemployment, lack of social grants, and lack of enough food are likely to influence symptoms reported. Most of these socioeconomic factors are beyond patient control in the rural context (26, 31).

In the current study, patients perceive their symptoms and illness depending on their health beliefs regarding the cause. This is in line with the underlying concept of the original Health Belief Model (HBM) that behaviour is determined by personal beliefs or perceptions about the disease and strategies available to decrease illness occurrence (22). Therefore, care seeking behaviour is targeted and an attempt is made to align it with the perceived aetiology of the illness from patients' point of view. The use of various health providers are also influenced by their social environment and beliefs of members of their social networks. In the context of patients receiving home care, their beliefs were modified by the care they receive from HBC. The anxiety experience triggers patience to seek care. Since all the patients in this study were enrolled in HBC, the support they received from CCWs substantially lessened their anxieties and burden of care this imposed on their families. Disruption in normal functioning caused by symptoms as experienced by the patient influences the decision to seek help (38-39).

4.3 Assumption of the sick role

Discussion of the symptoms with the significant others such as PCGs, friends and family members plays a crucial role in determining the response to illness. Health beliefs of significant others and their role in lay discussions prior to the seeking of professional care, influence how patients accept their illness and where they seek help. Furthermore, lay consultations with significant others guide patients in decision making concerning their choice of therapy (40). Other research in Africa complements the findings of this study that most patients appear to need the support and reassurance of others in the family before they recognize and accept illness and seek medical care (4, 17, 20). Furthermore, CCWs add a unique dimension of lay consultation.

4.4 Medical care contact

Patients in the study cope with a variety of physical problems, depending on the stage of their illness and disease. However, for all patients with chronic conditions particularly HIV, the physical and medical needs are numerous. Treatment for symptoms at times require frequent visits to hospitals or clinics, and this was beyond patient control though some patients in the current study (15 out 32) were receiving social grants. Such repeated visits to the clinics and hospitals combined with loss of income resulting from ill health pushed patients into deepening financial crisis. In spite of receiving some grants, patients in the study relied on financial support from relatives, neighbours and at times CCWs. However, those patients who had no income or assistance coming into the household reached extreme situation, unable to get enough food or pay school fees. The increased expenditure due to illness leading to inadequate food and problems in keeping children at school have been reported by other studies conducted in Africa (16, 41). Research has shown how important social grants are in protecting household health against socioeconomic impacts of change (34, 42-43). However, there are many barriers that prevent access to these grants. Barriers to access include lack of proper documentation, unmanageable distances to offices and low educational level of household head (43). Therefore, decentralization, particularly of HIV/AIDS services, to primary health care and local facilities may help to enhance access to care for most people in rural areas.

Meanwhile, access to ARVs and other drugs for patients in Bushbuckridge is still faced with challenges of poverty, which include lack of food to ensure acceptability of drugs and quality of care. Research by Majumdar and Mazaleni (2010) in Eastern Cape province of South Africa found lack of food as one of the major factor that negatively impact on the quality of life for people living with HIV/AIDS (4). Another research in Nigeria, by Agbonyitor (2009) also found inadequate food negatively affecting the quality of life of patients (16).

Sources of health care in this study indicate a predominant use of the public sector. Despite the predominant use of the public sector, and as their illness progressed, participants used both allopathic and traditional medicine (medical pluralism) at some point during their illness. Meanwhile, the medical care contact produces clear cut diagnosis and prescribed course of treatment for most patients. The finding that patients were switching or shopping for medical providers is a well-known complicated pattern, which has ability to delay access to care and support services for some patients, not only in Bushbuckridge but in other rural areas in South Africa (8, 18, 21, 31). It seems that the recurring of symptoms and negative impact of illness on patients' lives and their inability to function effectively have been important factors in influencing the decision to use alternative health care. Other reasons for switching care may include lack of accessible services and diagnosis, lack of information, stigma and denial (23, 31, 44). There is support from other studies for the findings in this research that people typically use other sources of health care to help ease chronic conditions rather than for acute or life threatening illness (45-47). Moreover, traditional practitioners operate largely outside of the formal systems, and they remain a frequent source of care for patients in rural areas in South Africa (31, 44, 48). The use of traditional medicine tends to be specific and appropriately related to the perceived aetiology of the illness (49). In the current study, some patients' used allopathic medicine for the illness they perceive as having natural causes and traditional medicine for the disease which they believe resulted from supernatural (bewitchment) or moral causes.

Making the decision concerning when and where to seek health has been shown to be a complex phenomenon (46-47). However, some HIV patients delay seeking health care on purpose while waiting to identify illness that may require medical attention, whereas others would be asymptomatic or unaware that they have symptoms. This is a problem, as patients visit health systems when they are already symptomatic, and this creates limitations for early

detection and diagnosis. HIV patients' narratives indicate that most felt that their behaviours did not place them at enough risky to deserve seeking testing, either because of their beliefs or denial. Delays in seeking care perpetuate medical pluralism (31). Furthermore, some delays are due to conditions beyond patients' control in the rural context. Other well-established barriers of access to medical care are related to the cost of seeking treatment, and the time and distance needed to travel (31, 50). In other cases, barriers were related to household socio-economic characteristics such as lower educational status, income, access to facilities and barriers as emotionally disturbed, fearful, anxiety, persistent stigma associated with care especially HIV patients, and traditional health beliefs that contradict scientific explanations, consistent with other studies (1, 20-21, 31).

4.5 The dependent patient Role

The acceptance of sick role is not easy for most people especially in rural communities where they are faced with various challenges. As the illness progresses, the major concerns were centred on the illness itself and the individual's future ability to recommence their previous work. The illness increased the dependency levels in many families as some patients lost their jobs. In some cases the illness caused family disintegration as some patients separated with their partners. The need for care increases when patients perceive their conditions interferes with their ability to function socially or physically in their life (50).

In the current study, patients (23/32) who reported that they were happy with their care givers (CCWs or PCGs), were more positive about life, and their treatment proceeded without too much complications. A sick role behaviour which refers to compliance or adherence to medical regimens usually following professional diagnosis is important in determining treatment outcomes. Patients who were in denial and shock reported poor health outcomes. It is unclear from the findings whether denial of the illness was the reason why other patients defaulted and

did not follow advice from CCWs or the result of other factors. However, according to literature, the experiences of illness may lead to suffering that interferes with work or fear of death that lead to social withdrawal (4, 8, 20). Patients, who were withdrawn, had poor social networks reported bad relationships with PCGs or CCWs received little or no assistance. It seems that CCWs, in most cases are successful not only in improving and helping patients accepting their status but also assisted in changing the attitudes of community and family members (16, 51). This is an important finding in view of stigma and discrimination that continue to surround HIV, although the study did not focus specifically on HIV stigma and discrimination. Furthermore, satisfaction was expressed with the medical care received, as majority of patients experienced symptom improvement once on treatment. However, further research is needed to compare the illness experience of patients with a chronic illness not receiving HBC with those receiving HBC.

4.6 Role of home caring

Education on the importance of adhering to treatment was delivered frequently by CCWs. Patients reported high levels of satisfaction with the advice, support and guidance they got from the CCWs. Once on treatment, patients adhere to their treatment and experience subsequent improvement in health. CCWs were able to address a wide spectrum of patient care needs. Several perceived barriers tend to deter participants from use of the public health sector, but CCWs encourage patients to visit the clinic/hospital for a variety of reason. Patients were helped with daily tasks such as bathing, eating, cleaning the home and at times preparing meals. As patients receive appropriate relevant information and care, they establish trust and remain with their health service providers (26, 52). Therefore, home care improves patient knowledge of disease process, signs and symptoms thereby enable easiest communication between the patient and the provider. Allowing patients to receive care in their familiar environment may lead to lower cost of care and provision of personalized culturally-appropriate care in the context of rural settings (51). Furthermore, home care has the potential to reduce

admissions, readmissions and may decrease the costs of providing care for hospitalization (26, 53).In line with the findings of this study, a study by Agbonyitor (2009) indicated that the support and awareness implemented through home care programmes has caused HIV/AIDS patients to see themselves differently through creation of supportive environments (16). Meanwhile, HBC programmes prove to be fundamental to the successful use of and universal access to HIV/ AIDS care and other chronic ailments (16, 31). Despite awareness implemented by CCWs, some HIV/AIDS patients experienced isolation, lack of acceptance and fear of disclosure. Previous literature has established that stigma and discrimination can be significant barriers to access adequate health care as well as psychological and social support (4, 31, 38, 54-56).

Other research also complements the findings of this study, in that the health facilities available in most rural areas in South Africa are under resourced and under staffed (4, 8, 18, 53). The effort of home care in the study setting was on provision of a continuum of care catering for the needs of various patients with information, counselling, health education, prevention and psychosocial support on basic medical care. While providing necessary care and support for patients, CCWs also increase community awareness and enlightenment on HIV issues by encouraging people to get tested early for HIV and to be screened for other diseases like TB. Patients with chronic diseases can live longer and function the greatest extent possible with proper care and services including the type provided by CCWs to patients in their homes (4, 16). Similar findings were presented by Majumdar and Mazaleni (4) in their qualitative study to explore the physical, emotional and well-being of people living with HIV/AIDS and their direct informal care givers, highlighting the need to develop HBC programmes that will enable those affected to cope with the disease(4, 16). However, home care is effective in monitoring patient response to planned treatment, can identify new problems which may not be easily identified through health systems, and can prevent or retard disability or death from illness (51).

4.6 Limitations of the study

This qualitative study of in-depth interviews has limitations. The data collection relied on patients to recall their illness experience. Although the use of participants' narratives is desirable as it allows patients to organize their experience and ascribe meaning to their life events, inevitably some recall bias results when this approach is used particularly among those patients with positive experiences. Another limitation was being constrained to secondary data, and one cannot make follow up to clarify themes as well as the possibility of not achieving thematic saturation. Also the lack of a baseline study or control group with which HBC organizations for comparison, and these patients may have a different experience compared with those receiving home care. No similar study was done in an urban area. However, due to resource limitations, it was financially impossible to include a control group. Such information could be important in providing a more holistic way of viewing the needs of patients in HBC. Furthermore, patients were interviewed face to face, and this might have caused patient to respond to some issues in a way they consider to be most socially desirable rather than answering with complete honesty. Lastly, because only 32 patients were interviewed from one rural community, the ability to relate the findings to other social contexts may be limited.

Chapter Five

5.0 Conclusion and Recommendations

5.1 Conclusion

This study contributes to the knowledge about illness origin, progression and response among home care patients. Most patients in HBC suffer from chronic illness, and these conditions are often associated with psychological and emotional distress. Furthermore, the chronic nature of their illnesses necessitates recurrent visits to health facilities for collection of medication. These multiple visits to clinics and hospitals are associated with socioeconomic implications, thereby placing further strain on the lives of these largely poor and illiterate rural patients. The rural context in which these chronically ill HBC patients find themselves tend to influence their beliefs about illness and the type of care needed, as well as the type of provider sought. However, the rural context also seems to largely avail a limited set of providers, perhaps due to shortage of health workers, and traditional healers are often used even by HIV patients. This might be the reason CCWs play such a key role in the lives of these patients and throughout the course of their illnesses, starting with confrontation and interpretation of symptoms, and the decision about health care. The role of CCWs go beyond illness experience to include care related to general well-being such as helping patients with food and hygiene in the households. However, there may be disadvantages as some indigent patients receive monetary and material support from CCWs, given the rampant poverty in this rural community, and the poor socioeconomic status of this CCWs. Notably, family members are also instrumental in lessening distress and anxiety for patients during their illness experience. Despite these issues, the quality, dedication and commitment of those working in home care, PCGs and CCWs as described by patients increase the positive experience of illness and enable patients to remain in their home and function to the greatest extent possible, given their health conditions.

5.2 Recommendations

- The findings of the study contribute to knowledge on the experience of patients in a poor rural population in Bushbuckridge. This information can help guide development of HBC programmes that are specifically tailored to the needs of patients in rural settings and relevant strategies to improve the quality of life and engagement in care. In order to achieve this, continuous, coordinated and integrated effort is necessary between the public health care facility, private sector and the community to facilitate service utilization and referrals to address some of the challenges faced by patients receiving home care.
- As seen in the study, poverty proved to be a significant barrier to health care for many patients since it reduces the patient's ability to provide basic necessities, particularly when government support is lacking. Policies and programmes need to be put in place for people with chronic illness in order to lessen financial toll of this illness and address the poverty of patients.
- Furthermore, putting in place income generating activities through government, NGO or donor communities could help patients and their caregivers to produce income.
- In order to develop a care system that is effective and sustainable in the context of under privileged rural communities, it would seem that more resources should be put into provision of HBC to enhance quality of life of patients.
- Moreover patients are being deterred from accessing allopathic medicine for example antiretroviral and other drugs because of the beliefs that contradict scientific explanations. Health promotion strategies need to take this into consideration and find means of accommodating these beliefs to improve access.
- The need for household and community early detection of symptoms and referral and compliance with effective treatment is imperative. Early recognition of symptom reduces death and disability from the illness.

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Appendix A: Interview Guide

RADAR
RURAL AIDS & DEVELOPMENT
ACTION RESEARCH PROGRAMME

UNIVERSITY OF THE WITWATERSRAND
SCHOOL OF PUBLIC HEALTH

P.O. BOX 2 ACORNHOEK 1360 - TELE: +27 13 795 5076 - FAX: +27 13 795 5082 - WWW.WITS.AC.ZA/RADAR

Patient: Interview guide

1. What has your experience been with your illness (Narrative)

2. What services and/or activities are provided to you with regards to your health care? (general and in-home)

3. Why are you being offered these services? How are these services being provided to you? (general and in-home)

4. More specifically, what types of services is _____ (CCG) providing to you? and _____ (PCG)? (Have the client elaborate on the services mentioned)

5. Are things going well in regards to your health care? What are some of the success? (E.g., likes, benefits, appreciates, progress)

6. Are there things that are not going well in regards to your health care? Or Challenges you are experiencing? (E.g., problems, difficulties, hardships, progress)

7. How do you feel about the nature/ state of care you receive?

8. How is your relationship with the CCW? How is your relationship with the PCG? How is your relationship with others involved in your care? (E.g., interactions with community, clinic, home, etc)
9. Do you have any suggestions you would like to share about caring for people who are sick in the home? Perhaps regarding needs from and services of both the CCW

Appendix B: Ethics Clearance for main study

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Dr Mosa Moshabela

CLEARANCE CERTIFICATE	**M090232**
PROJECT	Investigate the Contributions and Attributes of Home-Based Care (HBC) in Rural South Africa
INVESTIGATORS	Dr Mosa Moshabela.
DEPARTMENT	School of Public Health
DATE CONSIDERED	09.02.27
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 09.03.30 **CHAIRPERSON** .....
(Professor P E Cleaton Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Dr M Moshabela

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

.....

Appendix C: Information Leaflet and Consent Form

RADAR
RURAL AIDS & DEVELOPMENT
ACTION RESEARCH PROGRAMME

UNIVERSITY OF THE WITWATERSRAND
SCHOOL OF PUBLIC HEALTH

P.O. BOX 2 ACORNHOEK 1360 · TELE: +27 13 795 5076 · FAX: +27 13 795 5082 · WWW.WITS.AC.ZA/RADAR

INFORMATION LEAFLET

Good day. My name is _____ (Name of Interviewer), from the Rural AIDS and Development Action Research Programme (RADAR), University of Witwatersrand. I ***invite you*** to consider participating in a research study aimed at exploring experiences of home based care in rural South Africa. Your participation in this study is entirely voluntary.

Before agreeing to participate, it is important that you read and understand the following explanation of the purpose of the study, the study procedures, benefits, discomforts, and precautions and your right to withdraw from the study at any time.

This information leaflet is intended to help you decide if you would like to participate. You should fully understand what is involved before you agree to take part in this study. If you have any questions, do not hesitate to ask me. You should not agree to take part unless you are satisfied with the information provided. If you decide to take part in this study, you will be asked to sign this document to confirm that you understand the study. You will also be given a copy to keep.

PURPOSE and PROCEDURES OF THE STUDY:

You are a community caregiver working with a non-governmental organization, a primary caregiver or a care recipient and I would like you to consider taking part in this research.The purpose of this study is to understand experiences of community care workers, primary care givers, and clients in rural South Africa.

The study will be performed in Bushbuckridge only and approximately 600 participants will participate in this study. All participants will be 18 years and older.

The total amount of time required for your participation in this study will be a maximum of approximately 2 hours.

If you agree to take part in this study, you will be interviewed on one occasion, or until you are satisfied that you have provided all of the information you wish to provide to the interviewer

The interview will be voice-recorded to ensure that the information you provide is captured well.

Besides the inconvenience of your time, there is no other risk or discomfort you will experience as a direct effect of the study. If you experience any discomfort during the interview, please alert the interviewer. You may be requested to consult a counsellor should you experience any psychological distress as a result of the interview.

Your participation in this study will contribute to medical knowledge that may help improve the quality of your home based care services and that of other community care workers abroad and locally.

Your participation in this study is entirely voluntary and you can decline to participate, or stop at any time, without stating any reason. Your withdrawal will not affect your quality of care. You will not be paid to participate in this study.

This clinical study protocol has been submitted to the University of the Witwatersrand, **Human Research Ethics Committee (HREC)** and written approval has been granted by that committee.

If you want any information regarding your **rights as a research participant, or complaints regarding this research study**, you may contact Prof. Cleaton-Jones, Chairperson ofthe University of the Witwatersrand, Human Research Ethics Committee (HREC),which is an independent committee established to help protect the rights of research participants at (011) 717 2229.

All information obtained during the course of this study, including personal data and research data will be kept strictly confidential. Data that may be reported in scientific journals will not include any information that identifies you as a participant in this study. If you have any questions, you may telephonically contact the Principal Investigator, DrMosaMoshabela, at 013 795 5076 or 0834943089.

Thank you for your time

Appendix D: Ethics Clearance for this study