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RESEARCH REPORT

TITLE

Exploring the role of preparation, training and support received by community health workers on their experiences of providing home based care in Bushbuckridge

A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of:

Master of Public Health (MPH)

School of Public Health

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CANDIDATE'S DECLARATION

I, Langelihle Mlotshwa (student number 376388) am a post-graduate student registered for the degree Master of Public Health (MPH) at the University of the Witwatersrand, School of Public Health.

I am submitting written work for the research report component of the aforementioned degree.

I hereby declare the following:

- I confirm that the work submitted for the above course is my own work, except where I have stated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.

Signed: _____

Date: _____

DEDICATION

I dedicate this work to all the community health workers in the Bushbuckridge sub-district who continue to provide selfless services to the local people of the area and their dedication towards being 'foot soldiers'.

Langelihle Mlotshwa

ABSTRACT

INTRODUCTION

Training and support for community health workers is envisaged to positively shape a better effective health care system at the grass root level. All community health workers need adequate resources as they scale up treatment and support for people living in poor resource settings. The aim of this research report is to explore how the preparation and support processes for Community Health Workers influences their role in delivery of home-based care services in the Bushbuckridge Sub district during the period of April- July 2010.

METHODS

This research is embedded in a broader study: the care in the home study, which is a three year mixed method study conducted in Bushbuckridge, Ehlanzeni District, Mpumalanga province. An explorative qualitative study design for this secondary analysis was used. Data was collected during the period of April 2010- July 2010. Nine organizations were purposively sampled with 18 of their randomly-selected community health workers interviewed. Inductive and deductive codes were both used to analyse the data.

RESULTS

Themes that were central to preparation, training and support of CHWs were: Who we are (Identity), What we do and how we do it (Approaches and functions), What we do not do and why (Limitations). Identity captured how community health workers felt they had been defined, as well as how they defined themselves. The way they approach the work they do and the challenges they

face while doing their work leads to challenges that can pose a threat in their everyday work, and they respond differently to such difficulties.

CONCLUSION

The study concludes that the preparation and support of community health workers are grounded in their identity status within the communities which they volunteer in. This process therefore contributes to the way in which they experience caring for patients or clients in their home environment either negatively or positively.

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TABLE OF CONTENTS

1. CHAPTER 1 INTRODUCTION

1.1 *Introduction* 1

1.2 *Background/Context* 3

1.3 *Problem statement* 4

1.4 *Justification of the study* 6

1.5 *Literature Review* *6*

2. CHAPTER 2 METHODOLOGY

2.1 *Introduction* 11

2.2 *Study Design* 11

2.3 *Care in the home study* 11

2.4 *Background Information of the study* 12

2.5 *Study population* 13

2.5.1 *Eligibility for participation* 14

2.5.2 *Sample size* 15

2.6 *Data Collection* 15

2.7 *Data Management* 17

2.8 *Data Analysis* 17

2.8.1 *Saturation* *18*

2.8.2 *Truth* *18*

2.8.3 Consistency 19

2.8.4 Researcher Reflexivity 19

2.9 Ethical Clearance 20

2.10 Dissemination 20

3. CHAPTER 3 FINDINGS

3.1 *Introduction* 22

3.2 *Characteristics of participants* 22

3.3 *Who we are* 24

3.3.1 *Community Insiders* 24

3.3.2 *Community Outsiders* 28

3.3.2.1 Recognition for knowledge/expertise 28

3.3.2.2 Confidentiality and Trust 29

3.3.2.3 Stigmatization 30

3.3.3 Community Brokers 31

3.4 *What we do and how we do* 35

3.4.1 Access to resources 35

3.4.2 Training 36

3.4.3 Organizational support 38

3.4.3.1 Monetary support 38

3.4.4 Direct &indirect impact from government support 40

3.4.5 Altruistic Motives 42

3.5 What we do not do and why 42

3.5.1 Inadequate skills 43

3.5.2 Limited Resources 43

3.5.3 Attrition of community health workers 44

3.5.4 Use of traditional medicine 45

3.5.5 Gender Issues 45

4. CHAPTER 4 DISCUSSION

4.1 *Introduction* 47

4.2 *Role of Identity* *48*

4.3 *Role of the State* 49

4.3.1 *Indirect services of the state* *50*

4.3.2 Direct service of the state *51*

4.4 Role of the community *54*

4.5 Role of the organization *57*

4.6 Limitations *58*

5. CHAPTER 5 CONCLUSIONS AND RECOMMENDATIONS

5.1 *Conclusions* *59*

5.2 Recommendations *61*

7. REFERENCES 63

APPENDIX

Appendix A Interview guide

Appendix B Information leaflet

Appendix C Informed consent

Appendix D letter for permission to use data

Appendix E Ethics approval letter to carry out research

ABBREVIATIONS AND ACRONYMS

CHW	Community Health Worker
HBC	Home Based Care
PCG	Primary Care Giver
PHC	Primary Health Care
VCT	Voluntary Counselling and Testing
HIV	Human Immunodeficiency Virus
AIDS	Acquired Immunodeficiency Virus
HAST	HIV/AIDS, STI and TB
TB	Tuberculosis
NGO	Non-Government Organisation
NPO	Non-Profit Organization
DSD	Department of Social Development
DoH	Department of Health
WHO	World Health Organization

DEFINITIONS

Community health worker (CHW):	The individual in charge of providing health care services such as patient referrals (to the clinic, hospital, social worker, police), educating communities on different diseases, social support, physical support to the patients in the home, who has been given minimal medical training, home based care, HIV/AIDS, TB and counseling as their basic training. He/she is affiliated to a home based care organization (Schneider et al., 2008, Gitomer, 2010).
Preparation:	All which CHWs do beforehand to get ready for their work. This involves what they do personally or what the organization they are affiliated to does for them. It also includes the different departments linked to their work and what they do to help the CHWs get ready for their work.
Support:	To maintain CHWs by providing means necessary for their wellbeing and their work. This involves a range of support from their families, patients, organizations they are affiliated to, the different government departments and stakeholders involved with their work. The type of support also includes emotional support, continued training, materials, as well as financial support.
Home based care:	Home based care is 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 (WHO, 2002)
Clients/patients:	The individual given care in their home environment by the CHW. For the purpose of this study client and patient will be used inter changeably.
Primary care giver:	The individual responsible for the daily task of taking care of the client. This person is typically a relative of the patient for example an aunt, uncle, sister, brother, mother, father, wife, husband and cousin.
Care economy:	Work done, typically in the domestic sphere, for example cleaning, washing, cooking, and taking care of the sick. It keeps the labour force fed and ensures society operates effectively. Often such work is unpaid and unregulated, yet it keeps the labour-force fed. (Elson, 1999)

CHAPTER ONE

1.1 Introduction

The trend of community health workers (CHW) caring for people in the home environment has increased through the years, especially in resource-poor settings. In many countries, this has not only altered dramatically the lives of many people living with HIV and/or tuberculosis (TB) as well as other diseases, but has also changed the way in which primary health care (PHC) is organized and delivered. South Africa has recently re-prioritized the importance of social determinants of health and primary health care, and begun to re-engineer primary health care in communities (Pillay, 2012). In these current policy debates, community health workers are once again acknowledged as important players in public health care. Barron et al., (2010) state that:

> They form a central element of reorganised and proactive community based services, shifting from a predominant focus on 'de-hospitalized' care through top down referral, to a systematic bottom up and comprehensive approach to households, in which community based services form part of coordinated inter-sectoral action at the local/ward level pg: 28.

Community health workers are arguably the most vulnerable cadre of the health system operating at a community level, who provide health care in the home or community in order to promote, restore and maintain a person's health while exposing themselves to the illnesses they encounter (WHO, 2002, Akintola, 2006, Agbonyitor, 2009). In sub-Saharan Africa (SSA), most community health workers and home based carers are women, often in their 40s or older, and need protection from exposure and transmitting diseases to their own families, where they are usually the primary care givers too (Rodlach, 2009, Akintola, 2010, Kang'ethe, 2009, Agbonyitor, 2009, Gitomer, 2010). While community health workers are expected to perform a certain prescribed set of tasks, some are not adequately trained for the

work that they need to do (Schneider and Lehmann, 2010). Further, across South Africa many community health workers are reported as unpaid, under- supported and undervalued within the system they work or volunteer in (Goudie, 2011). Also given the elevated need for health care in light of the HIV and TB epidemics and growing burden of non-communicable disease in South Africa and elsewhere, community health workers require adequate knowledge, skills and competencies to provide the necessary health services to their communities. Although recognized through the national home based care guidelines, adequate training of community health workers is essential (DoH, 2001). Currently, not all community health workers receive adequate training in South Africa (Akintola, 2010, Languza et al., 2011).

Although properly trained community health workers are envisaged to positively shape a more affordable, accessible and effective health care system for people living in rural areas, they often have to rely on inadequate resources and support to achieve this (Gilson et al., 1989). Beyond needing to improvise, Gilson et al, (1989) reported that the irregular availability of supplies such as medical kits contributed in lowering the morale of community health workers. Two decades later there is little or no change as many community health workers still work without these essential resources (Rodlach, 2009, Russel and Schneider, 2000). Another challenge is that, while some community health workers are well integrated into formal health care facilities, others still struggle with lack of acceptance from staff in health facilities (Schneider and Lehmann, 2010). All the issues that are involved in improving the work of community health workers will require an active process of 'learning by doing' accompanied by intensive monitoring and evaluation (M&E) in the early stages and gradual refinement of the policy over time (Barron et al., 2010).

1.2 Background/Context

South Africa, a country with a population of about 50, 7 million (StatisticsSA, 2012), has a history of apartheid that has shaped the current health-, economic- and social-hardships, especially for those living in rural areas. The country faces an enormous task of correcting these injustices and inequalities (Hendricks and Nsebeza, 2010), for example health inequalities, where there is an unequal distribution of health resources and outcomes around the country. Non-governmental organizations (NGOs) and community based organizations (CBOs) have formed in South Africa over time, particularly in rural areas, to assist in channeling resources to black people (Galvin, 2010). Like many rural areas, Bushbuckridge was adversely affected by apartheid and was subsequently designated as one of the presidential nodes in 2001 (Harmse, 2009). This meant that special state attention would be given to this area, as it was perceived to have suffered a great deal due to apartheid. CBOs were formed as a means of social change within communities in the area (Galvin, 2010). Home based care organizations in Bushbuckridge, which aim to bring health resources closer to communities were also formed as part of such initiatives, fuelled by the rising HIV/AIDS epidemic (Gitomer, 2010).

At the time of this study, 37 home based care organizations in Bushbuckridge were identified, where as many as 938 community health workers volunteered in these different organizations (Gitomer, 2010). The offices of these home based care organizations were located in 35 different villages and their work extended to 241 villages throughout the sub-district. Of these 37 organizations, 22 were funded either by private funders or government bodies- mainly the departments of Health (DoH) and/or Social Development (DSD) - and 15 did not receive any funding. In all 37 organizations, personnel did not have any formal employment but only volunteered. Those working for organizations funded by government agencies received a stipend of either R500 or R1000 monthly from the DoH and/or DSD, and very few received

private funding (Gitomer, 2010). Some organizations were functioning well despite lack of funding; however this did not mean that they were not in need of funds that would make better the work that they did.

In 2006, after the administration of Bushbuckridge was controversially moved from Limpopo province to Mpumalanga province, DoH suspended some activities in this sub district due to lack of resources, as well as the need to direct resources to other districts which they felt had a greater need (Gitomer, 2010), fundamentally changing the dynamics of home based care in the area. Some of the organizations stopped receiving funding, some had less support of social services such as food parcels for their patients, and some did not receive any training after they were transferred to the new province. Organizations complained that the work they did would become substandard if not supported the way they have been in the previous province (Gitomer, 2010).

1.3 Problem Statement

Within the Department of Health's broader approach to health care community health workers form part of the service delivery teams within the District Health System (DHS), promoting Primary Health Care (PHC) and Community-based Health Services at the grass root level (DOH/DSD, 2009). This however requires strong community engagement and formal investments in the national health system, in order to get resources to those that may not reach them, particularly the rural communities. Policy reforms need to emphasize on re-organizing resources for community health workers to assist in improving their work at the community level.

It has been noted that there has been uneven development of community health worker programs in different provinces in South Africa. The supervision and support varies, with some provinces requiring their community health workers to report and account to primary health care facility staff while some have their supervision entrusted to NGOs or the

Department of Health (Languza et al., 2011, Goudie, 2011). There is a lack of uniformity in the training of this cadre, and limited or lack of support from organizations that should be providing supervision and other forms of support in the work that they do (Schneider et al., 2008, Languza et al., 2011, Goudie, 2011).

Furthermore the preparation for their work and training process does not always adequately involve community health workers, leaving them unable to properly perform their tasks (HRH Strategy for the Health Sector: 2012/13-2016/17). Unavailability of resources such as kits and nappies hamper the work that they do. In addition psychological preparation is critical for this cadre to work efficiently in dealing with the different challenges they encounter, and this is often inadequately addressed through the training on offer (Akintola, 2008, Kironde and Klaasen, 2002, Johnson and Khanna, 2004).

The lack of regularity in the ways community health workers are utilized and supported makes it difficult to compare and systematically analyze their influence (Schneider and Lehmann, 2010). There is a need to guard against potential unfairness in the distribution of health care resources, opportunities and systems at a household level, while still upholding the principle of economy in health care given that public health resources are not infinite, particularly in rural and remote settings (NDoH, 2004, Wimberley, 2006).

As the government of South Africa re-engineers primary health care to a level were health is accessible to all its citizens, it is crucial to identify issues around the support and preparation of community health workers. This knowledge and understanding of the work of community health workers is essential for the planning, development and implementation of voluntary community programs related to home caring. Policy direction for management of resources and the care economy for community health workers will also require close monitoring to ensure the improvement of their work. The current research findings will identify critical

issues within policy that need to be reconsidered as well as areas that will need further research.

1.4 Justification

Community health workers are essential in providing services to communities especially in resource-poor settings, as an extension of the health care system (Johnson and Khanna, 2004, Agbonyitor, 2009). However their work entails performing a wide range of activities that are stressful and overwhelming (NDoH, 2004, Akintola, 2006). Community health workers volunteer in different conditions that can influence their work in a positive or negative direction.

Understanding and addressing concerns regarding how community health workers are prepared for their work and how this influences their role in delivering home based services is important. This can assist with tailoring policy in support of the work that they do, especially effective if community health workers are themselves involved in policy development (Daniel et al., 2012), considering the limited public health resources that exist. Addressing all these issues also means better provision of primary health care to all especially in areas that are rural and marginalized where need is highest.

1.5 Literature review

Sub Saharan Africa faces a huge shortage of human resources for health, a situation that is worsened by the overwhelming demands of HIV/AIDS and TB that has affected the region tremendously (Kironde and Klaasen, 2002, Johnson and Khanna, 2004). Planning the workforce for the health service is challenging and complex. However planning is an important process and has to be done efficiently (HRH strategy for the Health Sector: 2012/13- 2016/17) (DoH, 2012). Community health workers have played an integral role in educating about, and providing treatment for, many different diseases at the community level (Johnson and Khanna, 2004, Rodlach, 2009, Akintola, 2010), as well as other activities

linked to the specific intervention they are part of (Clark et al., 2008). The training of community health workers has proven to be a big challenge, as they are often sent out to communities with inadequate skills to do their work (Akintola, 2008, Schneider et al., 2008). This, in turn, has contributed negatively to the quality of care people receive as the skills needed to perform these duties are often unavailable or inadequate (Languza et al., 2011).

Internationally, as part of the promotion for primary health suggested in the Alma Atta declaration in 1979 to increase basic health services for all, community health workers were touted as the solution (Simon et al., 2009). The Alma Atta declaration also suggests that health needs to be distributed equally, affordable, as well as accessible, to every individual across the board (Hassim et al., 2007, Hattingh et al., 2006); community health workers are seen as central to delivering primary health care as the grass root level (Goudie, 2011). Combating diseases at this level is also seen as important and community health workers can assist countries in achieving the millennium development goals (MDGs), as the principles of community health work are comprehensive, all-encompassing and cover an individuals' life span (DoH, 2001). Thus the use of community health workers can impact positively on countries in dealing with diseases and achieving their MDGs.

Historically, the South African health system has been caring for people in the home for more than fifty years (Tillekeratne et al., 2009, NDoH, 2004, Clark et al., 2008), predating, yet formalized by, the Alma Atta declaration in 1978 when community health workers were mainly introduced through non-governmental organizations (NGOs) to serve their communities (HRH strategy for the Health Sector: 2012/13- 2016/17) (DoH, 2012). Community work emphasizes the accessibility of social and health care services based on community participation as well as networks within the community. Caring for people in their homes also emerged as a result of financial considerations and cost effectiveness in South Africa (Bailey, 1996). Less formally, the need for resources has driven many

community members to form community-based structures as a way of survival for their communities (Galvin, 2010).

Until recently, community health worker roles have been varied and not defined clearly in national Human Resource for Health (HRH) policy. However, a policy, which places community health workers central to the primary health care initiative of re-engineering primary health care in communities, attempts to do this (DOH/DSD, 2009). It is important that community health workers are well trained and supported for the new policy to be effective in the work that they do. Although previous DoH policy labelled this cadre "volunteers", voluntary work is not free. It has opportunity costs that are taxing on the different lives of these individuals who give up their time, sometimes money, ostensibly for the 'good' of their communities (Johnson and Khanna, 2004, Akintola, 2006, Rodlach, 2009, Kang'ethe, 2009), and their own improvement and employment potential, as well as personal growth (Akintola, 2010, Kironde and Klaasen, 2002). Unemployment levels are high in rural areas (Collinson et al., 2006, StatisticsSA, 2007) therefore volunteering in order to get experience and become more 'employable' is a personal growth strategy for many community health workers.

Great inequalities exist in South Africa in accessing health services (HRH Strategy for the health strategy: 2012/13-2016/17). Among provinces and between rural and urban areas, health resources and personnel are limited and unequally distributed with rural and marginalized areas suffering the greatest strain (HRH Strategy for the health strategy: 2012/13-2016/17), compounded by the racial and spatial segregation of the apartheid past where black people were not afforded the same health resources as white people and rural areas were deprived (Hassim et al., 2007). With many South Africans still living in rural areas (Strauss, 2003) access to quality health care remains but a dream although, over three decades ago, health was declared a right (Hassim et al., 2007). The lack of resources within

such rural communities can be reduced by recognizing the formal contribution that community health workers can make to the health system. There are, however, many concerns about community health workers and these concerns need to be addressed in policy as well as service delivery plans which relate to their work (NDoH, 2009). Addressing these issues, including ongoing training, links to government departments as well as home based care kits will make their work more effective and efficient.

Despite the growing sense of self-worth among community health workers as well as the positive changes in the environment, many are dissatisfied (Schneider et al., 2008) although some have shown resilience in their work (Akintola, 2010). Many studies have shown that resilience in difficult working conditions is often created and sustained by the altruistic motives that this cadre has towards the people that they live with (Rodlach, 2009, Akintola, 2008, Languza et al., 2011). However, South Africa has not in past years developed support systems for community health workers and many will be lost to other organizations or departments who offer better career opportunities (Languza et al., 2011). However the recent primary health care initiative suggests that many of these individuals will be supported as they will work under a primary health care outreach team where monitoring and evaluation will be highly prioritized (Barron et al., 2010). Also government aims to play a more direct leading role in activities of community health work in order to strengthen the health system.

Women have been reported to comprise the majority of community health workers (Glenton et al., 2010, Agbonyitor, 2009, Kang'ethe, 2009, Akintola, 2006, Rodlach, 2009, Makina, 2009), yet they are often vulnerable and open to possible exploitation by the system in which they volunteer. Feminists have expressed their concern for such women caring for the sick without remuneration, noting that this may well throw the carers deeper into the pit of poverty (Finch, 1984, Kelesetse, 1998). In rural areas in South Africa, this concern is compounded by the harsh conditions of rural life, which is usually characterized by a lack of

resources, living as a single parent or away from a spouse who is a migrant worker (Wimberley, 2006, Thom, 2004). All these situations are stressors to women and need to be taken into consideration when preparing them for, as well as supporting them in, the work that they do (Akintola, 2008).

Studies have not reached a consensus and debates continue, on issues around community health workers' preparation and support for their work, and how it affects their service delivery. As South Africa begins to re-engineer primary health care with the role of community health workers central to this initiative, it is essential to consider these issues as this will strengthen the work community health workers do and ultimately the health system.

Study aim and objectives

The aim of this research was to explore how the preparation and support processes for community health workers influence their role in delivery of home-based care services in the Bushbuckridge Sub district during the period of April- July 2010.

Specific objectives:

The objectives of the research study were:

1. To describe the preparation process received by community health workers in caring for clients receiving home based care in the Bushbuckridge sub district during the period April-July 2010.
2. To describe the nature of support received by community health workers in caring for clients receiving home based care in the Bushbuck sub district during the period of April-July 2010
3. To explore the influence of preparation and support received by community health workers on their experiences in caring for clients receiving home based care in the Bushbuckridge sub district during the period of April-July 2010.

CHAPTER TWO

Methodology

2.1 Introduction

This chapter covers research methods that were used in this study, including describing the study area, study design, sampling method, sample size, data collection data analysis and ethical clearance.

2.2 Study Design

This piece of research is embedded in a broader study: the care in the home study, which is a three year mixed-method study exploring the quality of home based care in the Bushbuckridge sub district. Data for this piece of research were collected during the period of April 2010- July 2010. For this piece of research, an explorative qualitative research design was used to explore how community health workers are prepared for the work that they do, as well as how this influences their service delivery to clients receiving home based care in the Bushbuckridge sub district. A guided questionnaire was used which consisted of open-ended questions (see Appendix A).

2.3 Care in the home study

The care in the home study seeks to understand the quality of home based care in rural Bushbuckridge South Africa, as well as the relationship of the community health worker, primary caregiver and the client. The study also explores ways in which the provision of care provided to the client by the community health worker can be improved by understanding the support they are offered as well as any training available for their work. Additionally, organizational challenges were investigated to help identify barriers that may facilitate more efficient and higher quality service delivery. The initial part of the project, in which this

research is located, was qualitative in nature to help explore the community health workers, clients and primary care givers perspectives of what quality of care is and the second part of the project was quantitative in nature, for which a data collection tool was developed based on the qualitative responses in the study. This report examines the data collected during the first phase of the study.

2.4 Background information on study area

Bushbuckridge is located in the Ehlanzeni District in the Mpumalanga province and situated in the rural northeast of South Africa close to Mozambique. The area is surrounded to the east by the Kruger National Park and to the North by Limpopo Province. Historically, it was made up of the homelands of Gazankulu and Lebowa. Gazankulu was designated for Shangaan- and Tsonga-speaking people and Lebowa for Northern Sotho/ Sepedi/ Pulane speaking people (Mayher and Raab, 2008). This area as a whole has mainly three languages SiSwati, Shangaan and Northern Sotho.

Bushbuckridge has a population above half a million, and 65% of this population is under the age of 24 years (Bushbuckridge Local Municipality IDP, 2009/2010-2011/2012). According to the Bushbuckridge Local Municipality IDP 2009/2010-2011/2012 and Department of Health 2008/09, the area has 34 Wards and 243 villages, three hospitals, two health centres, 34 operational clinics and five mobile teams. Eighty four percent of the population earns less that R1300 (US$ 163) per household in a month(Mayher and Raab, 2008) and unemployment is a core development challenge in the area (Bushbuckridge Local Municipality IDP, 2009/2010-2011/2012). Furthermore, 40% of adults in the area have no education (Saloojee et al., 2007). The area is dry and overpopulated, with plots too small to support subsistence farming (Saloojee et al., 2007). In terms of health indicators, Bushbuckridge has performed

poorly and, in 2001, was designated one of the 13 rural nodes of South Africa for up liftment by the Presidency (HSTReport, 2005).

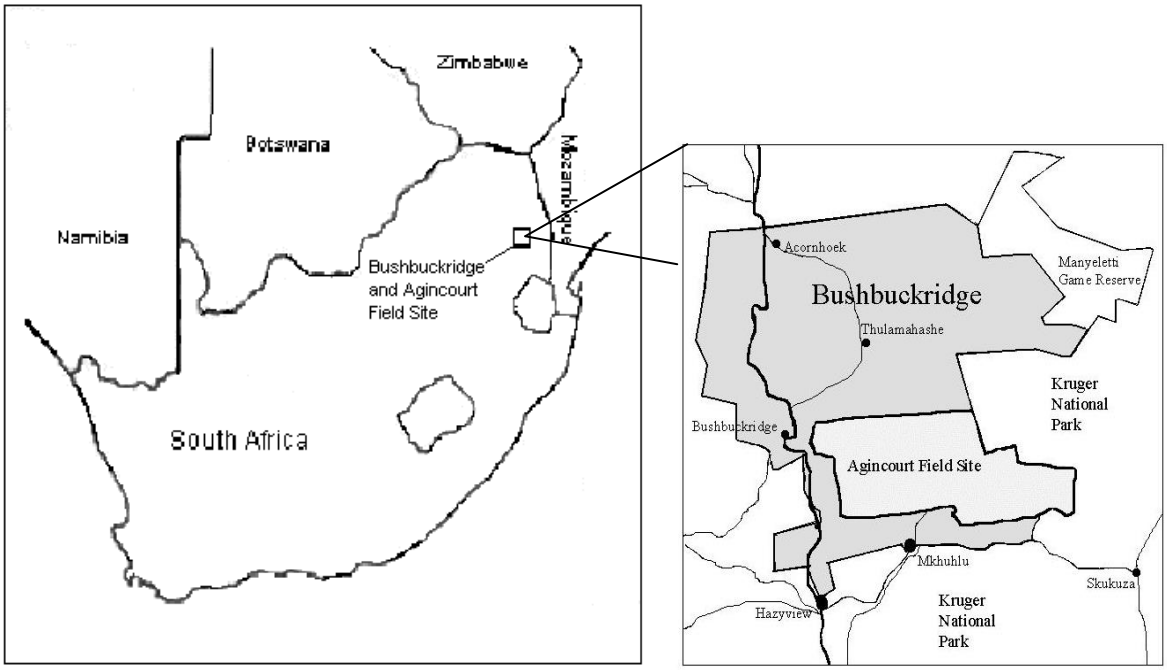


Figure 1: Map showing the Bushbuckridge Sub-district

2.5 Study population

The care in the home study carried out a situational analysis which identified 37 home based care organizations that were operational in the Bushbuckridge Sub district. Of the 37 organizations, 938 community health workers were identified as registered in home based care organizations. The community health workers typically volunteered 5hours a day within the communities they lived and sometimes away from their own communities.

Accredited and non-accredited training was offered to community health workers within organizations. The DoH was providing informal training (non-accredited) whenever they could, while private organizations and the DSD were providing the accredited, as well as the non-accredited, training.

Many of these organizations started as care groups by individuals, including retired pastors and elderly women who identified a need within the community. The community health workers provided care for patients with HIV/AIDS, TB, chronical illness, mental health issues, the elderly, malaria, people with disabilities, as well as orphans and vulnerable children, in their communities. Their duties varied depending on the patients' needs but mainly consisted of washing clothes, bathing clients, cleaning the house, health education, dressing wounds, transporting clients to the clinic or hospital, cooking for them, and providing them with comfort (Gitomer, 2010). With time, the organizations grew and became formalised and registered with the DoH. However not all the organization have non-profit organization (NPO) certificates to validate that they are registered organizations.

All community health workers in the area volunteered under the supervision of a management team per organization. The management team in these organizations consisted mainly of the manager, secretary, finance person and coordinator whose duties included monitoring community health workers while engaging in their work. The 938 community health workers in the home based care organizations in Bushbuckridge at the time of study was the study population.

2.5.1 Eligibility for participation

Community health workers who were eligible to participate in the study were all the community health workers (938) who were registered with the home-based care organizations in the sub-district.

2.5.2 Sample size

A sample is a subset or smaller set of a larger population that has been selected for inclusion in a study (De Vos et al., 2011). For this research, a total of 18 community health workers were purposively sampled from nine different home based care organizations. The 18 participants were sampled according to their sex, age, the length of time working as a community health worker, the disease(s) they dealt with, whether they received a stipend or not, training received, education, and if they worked in the village where they lived.

2.6 Data Collection

Three teams of two research assistants', each comprising four females and two males, with graduate students as team leaders, were trained in administering the tool for the collection of data. A semi-structured open ended interview guide (see Appendix A) was used to conduct the interviews in the local languages (Xitsonga or Northern Sotho or siSwati) and the participant was asked which particular language they were most comfortable in. An interview guide identifies important questions to serve as a check list so that the interviewer does not leave out essential questions while conducting the interview (De Vos et al., 2011) and to assist the interviewer in guiding the interview process but without leading the participant. Additionally, semi-structured interviews:

- ✓ Permits comprehensive and comparable data gathering ensuring that all main issues are covered.
- ✓ Nonverbal behaviour, expressions and communications can be obtained.
- ✓ It is a person-centred approach as interviews are face to face with interviewees.
- ✓ It allows follow up interviews, probing as well as clarification of any issues that have not been understood.

- ✓ Questions can be changed depending on the flow of the interview and this helps the interview flow smoother.
- ✓ Such interviews gather in-depth information through the process of probing; this also leads to the researcher being able to obtain personal, sensitive and complex information. (De Vos et al., 2011).

The researcher was part of the team collecting data as an observer in the interviews. She also collected notes in her journal of any interesting phenomena within the surroundings as well as any physical or facial expressions by participants during the interview, important for adding to the context of the interviews.

Data collection was carried out from April to July 2010, during times that community health workers were available. The interviews took place at the community health workers' homes or where they were most comfortable, for example the clinic. This would ensure no interruptions during the interviews. Measures were taken to ensure that these interviews were conducted in private and that confidentiality was assured.

The management team of each organization was informed about the interviews that would take place. In every organization, efforts were made to ensure that the research was explained to community health workers, using non-governmental organizations (NPO) meetings, HIV/AIDS, STI and TB (HAST) meetings as well as organization meetings prior to the data collection, so that everyone understood what the research was about and no negative ideas would spread within the communities about the study.

Participants were informed about the purpose of the study as well as the nature of the interviews. The information sheet (see Appendix B) was read to the participant and the participant was also provided with a copy in their preferred language. Written consent was

obtained from each individual to participate in the study (see Appendix C) and separate consent obtained to record the interview (see Appendix D). All the participants were assured their confidentiality would be protected and informed that they had a right to withdraw from the study if they felt they did not want to participate anymore.

Key questions asked included: tell us about yourself, your background; how did you get started in home based care; how did the organization help prepare you for your work; how does the organization support you and your work and what does your typical day look like amongst other questions. All interviews were tape recorded to ensure accurate data capture. A field journal was kept by each research assistant to write observations from interviews, and thereby add context to the study.

2.7 Data Management

All recordings were transferred to computers and labelled accordingly by the research manager. The audio files were stored on password-protected computers and saved under the pseudonyms given to the respondent. The research assistants then transcribed and translated verbatim the interviews. Observations from interviews were also included in the transcripts to add to the context of the interviews. To ensure quality of the data collected and transcribed, three independent researchers exchanged transcripts and all discrepancies were resolved. All transcripts were then de-identified to ensure the privacy of the individuals.

2.8 Data Analysis

The transcripts were analyzed using both deductive and inductive codes. Inductive codes use the data to generate ideas while deductive codes start with a preconceived idea or theoretical framework and then use the data to verify or disapprove the ideas (Holloway, 1997). Deductive codes were used to construct aspects of the interview guide and were drawn from

the wide literature on the subject of community health worker training, such as the selection of community health workers, training of community health workers, population and service coverage of community health workers, nature of employment or career prospect and incentives of community health workers, gender or masculinity issues of community health workers, feedback, monitoring mechanisms and community participation of community health workers. The inductive codes emerged from the data through issues that were raised by participants (Hennink et al., 2010, Hsieh and Shannon, 2005). The inductive codes are important as they reflect the issues that were most important to the participants (Hennink et al., 2010), issues that confirmed, or were unexpected or different from, literature. The verbatim transcripts were systematically and coherently coded, then developed into sub-themes and themes (Joubert and Ehrlich, 2007, Li and Seale, 2007). This ensured that the data was left rich and meaningful, connected to the research question (Joubert and Ehrlich, 2007).

An excel sheet was utilized in order to track all codes developed, their consistency (Li and Seale, 2007) and type, and examples from data to ensure that each code relevant to the research question was captured (Hennink et al., 2010).

2.8.1 Saturation

Codes were developed until saturation was reached, when no more new information was emerging from the data or interviews during coding. The codes were thus representative of a wide range of the data (Starks and Trinidad, 2007).Key issues were drawn out from the themes identified and the interpretations are presented as part of the results in this report.

2.8.2 Truth

'Truth' in the context of this research – a qualitative, exploratory study - means that the researcher is sure and confident that the results or findings are a true and honest reflection of the study participants views, thoughts and experiences in view of the research design. It is

also important to note that qualitative research of this kind does not assume there is one singular truth, but rather that each individual has their own truth formed by their own world and identity. In this research, truth was achieved by:

- ✓ Codes checked by an experienced independent coder (supervisor) to confirm the researcher's own analysis of the transcribed data.
- ✓ All interviews were tape recorded to capture verbatim account by the participants (Krefting, 1990)

2.8.3 Consistency

Consistency is a strategy that ensures results are dependable in qualitative research, the measure used includes:

- ✓ A detailed description of the research methodology used which also includes the questions and themes that have been provided.
- ✓ The independent researcher (supervisor) who assisted in verifying the researcher's codes and analysis.

2.8.4 Researcher reflexivity

Researchers often make assumptions and project their own beliefs and biases on subjects being researched on during the research process(John and Dana, 2000). It is therefore important for a researcher to be conscious of this and acknowledge and describe their own beliefs and biases as a way to establish trustworthiness or validity through the research process. As the researcher as well as observer during the interviews, I noted issues that could influence my understanding and interpretation of the data and my understanding of the communities themselves, having had time to live and interact with them. Also being a black young woman, educated and foreign could influence my understanding and interpretation of the data. Having looked at the data again and again, I challenged my thoughts constantly,

especially whenever issues relating to possible bias emerged. Clarity was also sought during follow up interviews with some of the participants.

2.9 ***Ethical Clearance***

Ethical clearance for the Care in the Home Study was obtained from the University of the Witwatersrand Human Research Ethics Committee, ethics number M090232. Additionally, the same committee approved and gave this component of the study ethical clearanceM120130, (see certificate, Appendix E).

Research participants have legal rights; including to informed consent. All information about the study was provided to all the participants regarding the aims, processes, procedures, advantages and disadvantages of participating in the research study (De Vos et al., 2011).To ensure confidentiality and anonymity of the participants' pseudonyms were used during data processing and reporting. The participants were also informed that their work within the organization would not be affected by their responses in the interview or their response to decline participating in the study. Therefore it was also the participants right to withdraw at any stage if they felt they did not want to participate anymore. After the participants were informed about the aims and the methods of the research, all participants agreed to participate verbally as well as with signed consent; a separate consent form was signed to allow the interviewer to tape record the interview. All the informed consent forms were taken and stored in a safe storeroom.

2.10 Dissemination

The findings of this study will be made available to the University of the Witwatersrand Library and the Rural and AIDS Development Action Research program (RADAR). A copy will also be submitted to the Department of Health Bushbuckridge sub-district. The findings

will also be published in a recognized peer reviewed journal as a journal article, as well as shared in conferences.

CHAPTER THREE

FINDINGS

3.1 Introduction

This chapter presents key findings of the study by describing the characteristics of participants, the training and support they received in providing home based care in Bushbuckridge. The findings are based on the interviews conducted with the community health workers who participated in the Care in the Home Study.

3.2 Characteristics of participants

The participants' characteristics are represented in Table 1 below. The proportion of female participants (89%) outweighed male participants (11%), mirroring the fewer male counterparts in home based care, a finding which was also seen in the bigger project and pointing to glaring gender differences in the study. One of the male participants reflected on this, drawing on gender stereotypes to suggest that it related to the 'type' of services rendered to patients because 'women are care givers within the home'. All of the participants reported that many of the primary care givers in homes where they worked were women - aunt, sister, mother, daughter, and wife - which further reflects the gendered representation of women as care givers in the home. Most of the participants had completed secondary education (72%) while those with primary and tertiary education were 22% and 1% respectively. At least 16 (89%) of the participants had been working in their current home based care organization for more than a year and reported receiving training for at least one of the services that they were providing to their patients. While the spectrum of training offered included care for the elderly, chronically ill, HIV/AIDS, TB, mental health, malaria, orphans and vulnerable children (OVC) as well as rendering services according to patients' needs individually, not all of the participants had received training on the full spectrum and therefore reported having no

training for some of the patients they needed to provide care for. All participants worked only as community health workers and did not report having an alternative source of employment. A stipend was received by just over half of the participants (56%), meaning that 44% did not receive any financial remuneration. A high proportion of the participants 15(83%) volunteered in the communities where they lived.

Table1: Demographic characteristics of participants

Sex	
Female	16(89%)
Male	2 (11%)
Age	
20-24	1(6%)
25-29	3(17%)
30-34	3(17%)
35-39	3(17%)
40-44	3(17%)
45-49	0(0%)
50-54	1(6%)
55-59	0(0%)
+60	4(22%)
Education status	
Primary	4 (22%)
Secondary	13(72%)
Tertiary	1(6%)
Length working as CHW	
≤1yr	2 (11%)
2-4yrs	6 (33%)
5-7yrs	8(44%)
8-10yrs	0(0%)
≥ 11yrs	2(11%)

N=18

Different themes and sub-themes emerged from the data collected on the role of training and support received by community health workers and their experiences of providing home based care. The themes that were reported were central to their identity:

1. Who we are (Identity)
2. What we do and how we do it (Approaches and functions)
3. What we do not do and why (Limitations)

3.3 Who we are

When speaking of themselves and their work, participants generally identified themselves as altruistic, committed, always working for the community and in a positive light. All the participants spoke about home caring in the same light despite having worked for a longer time or a shorter time in home based care. It was as if the older ones influenced the way they perceived their caring duties as well as their personal situations. In contrast, they felt their communities identified them slightly differently - as people with knowledge, information, access to resources, and sometimes, more negatively, as lacking confidentiality. Identity emerged as an important theme: how community health workers see themselves and think others see them - influences their experiences in caring for home based patients, and how they understood their work, as well as the training and support they received. Key components of this theme included community health workers as community insiders, community outsiders and community brokers. These sub-themes account for the mixed feelings expressed by participants, as they felt part of their communities on the one hand, felt they were treated as "outsiders" due to their work in the community. This tension between being inside and outside, and somehow in-between, was a key component in their narratives which influenced their caring for patients in their home environment.

3.3.1 Community insiders

Participants spoke of themselves as community insiders, part of the community they were working in, often having lived and grown up with many of the community members. An

attachment formed by some, from birth or early years of childhood or through marriage, created a viable bond – from their perspective - with community members. Living in the community with family members, either from their nuclear or extended families, was also, for many grounds to affirm an insider status.

"…. I am Noria, I was born here at [name of birth place], on [date of birth].Mm… I am a care giver at [same as birth place]…" *Noria, Female, 35*

The participants reported that within the communities where they lived, relationships were formed amongst neighbours, which, for them, often resulted in mutual assistance and support. Central to the life stories of most participants was the notion that being part of the community was more than being a member of a geographic space, but rather, understanding people's needs and helping if need be. This, in a way, prepared them for the work that they did. As they were insiders of the community they learnt to take care of each other before even beginning to be formal community health workers. This was the case for Tinstwalo who volunteered in home base care for seven years and communicated the importance of living a life of service.

"…We must help the community; that's the first thing. Secondly, taking care of the patients, thirdly, taking care of the orphans and making sure they are at the right place. Fourthly, the patients we find at random must be referred to the clinic or hospital…"

Tinstwalo, Female, 62

Some of the participants spoke about supporting, or being part of, community structures such as forums that serve the purpose of community development. Active engagement with community programs according to the participants assisted them in fulfilling their own need to contribute to community development.

"…I was born here in [name of place] in 1949. I have grown up in [same as birth place] and started to help people. In 1976 I joined Women's league…"

Gloria, Female, 61

"…I was part of the community Development Forum in [name of place] where [name of person], the founder and manager of [name of organization], came with an idea to start a Home Base Care organization…" *Phumzile, Female, 21*

Like Phumzile, many of the participants were informally admitted into their present work, through, helping the sick or neighbours with different problems.

"… I heard that they [the HBC organization in her area] are looking for a person to work with them, therefore I went to ask to work with them and they agreed. Before this I was taking after care of my mother. There was a child who was suffering from Asthma and I was also taking care of that child because they were staying together with my mother. During that time the experience inspired me to help others who are suffering from different illnesses.

Dethapelo, Female, 37

Church was also a place where participants reported interacting with many community members, which allowed them to have a sense of belonging in that particular community. Religion played an important role in their narratives as this also emphasized the need for caring for others 'as God would expect of them', an expression of a religious calling to service.

"…Firstly I'll say it's the power of God. What happened is that when I was home the pastor came to me to say that they were looking for help at church. When I arrived there they told me that they wanted me to help with caring for people in the community; that is working at the Home Based Care organisation. I accepted the offer and this is how I started working

there…"

Tintswalo, Female, 62

Participants as community insiders also mentioned that their bonds were formed in the schools – mostly within the community - they had attended. For them, a connection with their patients did not begin when they were community health workers but rather because they were from the same background and interacted at a more social level in the community.

Many also commented that their day-to-day experiences as community members and community health workers were similar in terms of the challenges that they face, for example, lack of money for food and other basic commodities. Doreen, one of the participants, explained how difficult the work got sometimes as she had no money to assist her patients who also had no money; this made them share and understand experiences at the same level and, for her this created a sense of spatial and social connection within the community among community members.

"…Our client's situation is not good and as we are also not earning there is nothing I can do. All we do is to give psychological support and nothing more. Sometimes we visit her and find that she doesn't have food in her house or money to go to the clinic to collect her treatment. That makes us to feel sad but there is nothing we can do at this point. We do wish to assist our client with other things but we can't…"

Doreen, Female, 28

However, while participants reported many similarities with community members and identified themselves as belonging in these communities, another sub-theme emerged around ways in which they felt they did not belong; that they were also "outsiders", often, many suggested, by receiving a status higher than an 'ordinary' community member due to their perceived knowledge about health issues.

3.3.2 Community outsiders

Although participants reported having a sense of being part of the community, they also reported a sense of being community outsiders. The participants felt this was because of their professional status within the community where they lived and worked. Many mentioned sometimes feeling isolated by the community members due to their work. Additionally, some of the participants reported patients did not always trust them because they felt that they would tell other community members about their problems. Despite participants having had spent a greater portion of their lives with these community members they still felt that they were not always entirely trusted or welcome in some of the homes within the community.

3.3.2.1Recognition for knowledge or expertise

Receiving recognition for their health knowledge and training was seen to elevate the status of participants within the community. For example, participants reported being defined as teachers, social workers and doctors *"…They see me as though I am a doctor and they are satisfied with the care I give the patient…"* because they could teach about different health issues, particularly TB and HIV/AIDS which seemed to be the most talked about health conditions, as well as sometimes connect social services to their patients.

Additionally, the participants spoke about their work having a positive impact within the communities, that without this work, many people would not get tested for different diseases particularly HIV and TB. Therefore, they maintained, their presence in the community as very important: "the dogs that sniff patients out" as one participant reported.

"...There is a difference [talking about her patient] because now her life has improved. She could have died, but her life was spared. I don't know if it was the government who started this initiative [home caring]. We are really grateful because patients didn't understand the

importance of getting tested. This caring business is really working. We are like the dogs that go around and sniff them out..."

Jennifer, Female, 43

3.3.2.2 Confidentiality and trust in their work

Although participants felt that community members recognised their knowledge, with a positive impact on their own identities, many noted that confidentiality – or the lack thereof - was a huge issue and this contributed negatively to them being perceived as outsiders. While participants reported the need for community health workers to be ethical when handling community members' issues, it emerged from their narratives that confidentiality was not always practised. Along with feeling isolated as a consequence, they also mentioned that a lack of ethical practice contributed to neighbours not trusting each other generally out of fear that people would begin to speak about other peoples' problems.

"...You find out that when you are neighbours you do not trust each other and you find that it is difficult for neighbours to share their problems..."

Dethapelo, Female, 37

Additionally, despite reporting the importance of practicing confidentiality, how they made sure they kept 'secrets' *"...the fact that I can naturally keep a secret [referring to patient confidentiality]..."* participants described being chased away from the yards of community members who feared being associated with the work that they perform. This, they felt was beyond 'just' keeping a secret but was largely because of the issues of stigmatization (particularly about HIV/AIDS and community perceptions related to the purpose of CHW visits) that existed in their communities. They felt this kept them at a distance or 'outside' of the intimate space of the home. At the same time within a context of high levels of stigma

(discussed below), they also noted that often, the patients that they served insisted on receiving their care without revealing their disease.

3.3.2.3 Stigmatization

Although some of the community health workers formed a relation of trust with community members, there were other members of the community that associated their work with nursing people who have HIV/AIDS. This, participants suggested, made the community more resistant to key health messages. This further manifested itself in the individual households where family members did not want to share utensils, food or even want to live with individuals who were diagnosed positive with HIV. They thought they would be infected if they did share these utensils and food.

"…One of her family members wanted to discriminate her but it did not go on for long…"

Tumelo, Female, 32

Living in a tightly knitted community means that news and rumours spread easily, and this was a big concern for participants. Community members needed to feel safe within their own community and participants needed to help guarantee that.

Some of the participants such as Olga felt their work was stigmatised as they had to deal with patients who did not want them (the community health workers) to be seen by other community members entering their homes. The biggest fear for the patients was the community talking about them, saying that they could have the 'disease' (referring to HIV). As HIV/AIDS is a highly stigmatized disease community members seeing participants walking around with HIV or home based care written T-shirts made them assume they only took care of such patients.

"…Some would refuse to be our patients…"

Thembi, Female, 40

Overcoming barriers and trying to accommodate social stereotypes in order to meet service delivery needs included community health workers delivering services to HIV positive clients in secrecy without knowledge from other community members.

"…Okay. I found Esther by going door to door and the day when I found her Esther disclosed her [HIV] status to me. Then I told her that is how I am going to help you and she told me that she would not like me to come to her place because she is selling traditional beer [this is when there are many people in her home that could see the community health work]. So we agreed on how we would visit each other [more privately]…"

Olga, Female, 60

In many ways, participants' life stories showed them as being not fully inside and yet still not fully outside of the communities that they serve. They were somehow 'in the middle'.

3.3.3 Community brokers

The sub theme community brokers also linked with the theme "what we do and how we do it" discussed below. The idea of them being the 'middle person' somehow helped connect resources to the community and do the work they had to do. The themes clearly overlapped and showed a relationship in the work that they did.

Many participants felt that community members saw them as a 'middle man' situated at the grass roots level between their households and the health care system. This idea of brokering two worlds, they felt, made the community look at them as in-between, not quite an insider and yet not quite an outsider. On the one hand, they felt the community expected them to have a deep knowledge of, and empathy with, the community, which gave them an insider

status. On the other hand, due to their professional status and medical knowledge, often linked to HIV, they felt they were both elevated by, and held apart from, the community. Additionally, the brokering process was presented as the community needs their help in accessing necessary facilities such as hospitals, clinics, social services including housing for the patients and other important facilities to them, yet, simultaneously, they are just another ordinary neighbour within the community. This, many felt, put them in a difficult position, especially if patients did not receive the services or care (often out of the scope of community health work) they expected. In some cases, participants reported that the patients began to dislike and distrust them. Participants described trying to balance themselves and roles in the community without losing their credibility while still providing for the patients.

"...I think if you don't have money at home this illness (HIV) becomes worse. The problem is they (the patients) start hating me when they don't receive the grant anymore. They think that when I go to them to get a report on how they are feeling I take this information to [name of institution or facility] so that they can cancel the grant because they are feeling well. They hate me when their grant gets cut off..."

Jennifer, Female, 43

The community, according to the participants, felt community health workers were connected with resources such as social services and could easily assist in accessing these resources so as to meet their patients' needs. While for some participants this was true, it was often entirely the opposite for others, who identified needing resources to do their work properly (this is explored in more detail under the theme "what we do and how we do it" below). As part of exercising their brokering in the community the participants reported pressure from patients who wanted food parcels from social services as they did not have food in their homes. Gloria was one of the participants who clearly had support and access to some of the resources that were important for their patients.

"…The organization helped us a lot with money, food, clothes and uniforms for orphans and vulnerable children..." *Gloria, Female, 60*

Some of their patients needed medicines and tablets from the hospitals or clinics, and sometimes participants had to take the patient to the health facility. Taking the patient to the facility assisted the patient in receiving quicker or easier care. This was because some of the participants' were known in different facilities for the work that they were doing in the communities. When they were present when taking a patient to a health facility they were able to explain clearly to the health personnel what the problem was, and more immediately receive assistance.

"…We take her to the clinic or at Rixile [HIV/AIDS clinic], so that we can find out how the patient defaulted. We work well together with them [the clinic] and the patient…"

Jennifer, Female, 43

However not all of the participants offered this type of care. Some reported that when a primary care giver was present then he or she would be responsible for doing such tasks.

"…Her daughter does all the cooking and cleaning for her. I just go there to check up on her and to remind them not to get tired of always taking the treatment and going to the clinic…"

Dethapelo, Female, 37

Participants also reported facilitating the need for receiving gloves or nappies from the clinic or the home based care organization for their patients, particularly for those bed ridden patients who needed to be cleaned and were unable to go to the toilet. These resources were important for daily work and were often in short-supply, although patients, participants suggested, thought they had these resources at their disposal. In all this however, participants needed to have a good referral system in place to make sure that they are able to get patients

to facilities as well as receive these needed resources from the clinic or home based care organization with no problems.

"…When we went to the families to monitor the adherence, people in the community just informed us that there is a sick person in that particular house. Then I went to the house they had told me about then there I found him sick and coughing, therefore I referred him to the clinic. He was then diagnosed with TB; from there I started taking care of him…"

Prince, Male, 44

Brokering also involved linking patients with organisations other than hospitals and clinics, including schools, social development; social services, NGO's, NPO's, police and other services that were deemed necessary for their work. The assistance they offered often stretched well beyond their scope as community health workers, to every individual who needed them in the community.

"…I also helped a child who passed his matric without his ID document. He told me that the teachers failed to help him to get an identity document. What I did, I told him to go to the primary school and to the high school to collect letters that he was attending there and he did as I told him to do. He went to [name of school] where he attended his primary level and then to [name of school] high school where the principal helped him to get the letter. Then we went to the police station and the Home Affairs offices and I explained that he does not have an ID document and the birth certificate…"

Gloria, Female, 60

Identifying themselves as people who were part of the community and at the same time outside the community also related to the work that they performed and how they performed it. This sense of 'in between' emerges in the themes of identifying how they actually

performed their duties and who made it possible for them to carry out these duties for their communities.

3.4 What we do and how we do it

The services that they offered were wide ranging, from household chores to taking the patients to the clinic or hospital for treatment to connecting community members with social services for those who are in need of it. Many who were able to provide these services felt they were of great value to the recipients and said that they were happy to do the job.

"…We help them if we find a very poor family we take their treatment book and collect treatment for them. Especially if the client is very sick and poor, we also try and ask the family if we can call an ambulance to get the client to hospital because at home there is no treatment…" *Doreen, Female, 28*

"…Well, I clean for him, I got him registered for food parcels with CDF and I gave him money to go to home affairs…" *Tintswalo, Female, 62*

3.4.1 Access to resources

Being equipped with the necessary skills and resources to do the work well emerged as a key theme. Yet many reported the challenge of working with no resources or minimum resources within impoverished communities in need of their assistance; it was a daily quest to improvise. For example, having gloves, to use either for patients or to clean the house for patients often proved difficult to get. Thapelo explained how the clinic, which was his source of these resources, would sometimes inform the community health workers that they did not have enough resources to share.

"…They were not able to give us things like gloves when we went to the clinic to explain that I came across something with such clients and I am looking for this and that to assist the

client. They would tell us that they have only stock for the clinic..."

Thapelo, Male, 36

While some participants reported such shortages in equipment, others reported that home based care organizations, clinics and hospitals provided them with necessary equipment to do their jobs efficiently.

"...We get bathing material from the clinic. If there is a patient that I need to be helping, I go to the clinic and ask for them. Gloves! I remember there was an old lady who didn't have anybody taking care of her. We would go to the clinic and explain to them. They gave us gloves so that if she made a mess we could be able to wear and sort everything out..."

Faith, Female, 29

Looking across the participants' narratives, there was unequal distribution of materials resources from organization to organization, although it was obvious that all of them needed the supplies, especially those with bedridden patients.

3.4.2 Training

Training was identified as an important pre-requisite for ensuring that duties were performed well. Participants reported that when they were trained, they felt equipped for the different challenges that are part of their daily duties, allowing them to have better solutions for their patients. Being trained to understand the patient and their needs was integral to participants; it made their work bearable in the midst of other challenges.

"...What I have mentioned before are the trainings that they were supported us with. Like myself I can mention that they helped me a lot because I did not have knowledge on those things and now I have gained a lot of information because of their trainings..."

Olga, Female, 30

Many noted that regular and on-going training would assist them to do their work well, as things change and new information on how to take better care of the patients would make a huge impact in their work.

"...I would like to add more training. How to care for my clients and how to carry the client or bathe him/her on my own..." *Phumzile, Female, 22*

Some of the participants emphasised the need for certificates after completing training, as proof that they had completed the particular training.

"...Since I am working under this home based care, I would like to have a certificate for home based care since I do not have any. Yes we did attend home based care training. This is the one that we are looking for. They trained us but they did not give us the certificate..."

Noria, Female, 35

After receiving their own training, some community health workers reported training family members of their patients to assist within the household when they were unavailable. Having an active primary care giver in the home made the load lighter for many of the community health workers. The participants who received such assistance from family members reiterated how working with these active primary care givers was a great support system for not only the patients but also them (the community health worker). It meant for them there was less work to be done in a particular household reducing the strain of their overall work. The participants also suggested that this gave them more time with patients who needed them more, for example, bed-ridden patients who did not have primary care givers. Additionally, adherence to medical treatment for many of the patients seemed to be much better with the support of an active primary care giver within the home.

"…In the beginning her mother was always away and my client did not have anyone to help her take her treatment well. As we all know that some old people don't give much support for the sick. But now my client's mother is giving her support and she is no longer taking her treatment from the clinic [she is now taking her treatment at home]…"

Tumelo, Female, 32

"…Now when we go there, we find that the person staying with them has done almost everything, but before we were sweeping, cleaning and fetching water and cooking…"

Busi, Female, 30

3.4.3 Organizational support

The participants explained that their work sometimes proved very difficult, and left them feeling de-motivated. However, they also felt that the organizations where they volunteered were very supportive and sought to ensure that the community health workers would work to their best ability.

"…They motivate us to be patient while volunteering and helping our community. They motivate us to be patient while working with the client. Even if the clients are not ill we have to visit them and give education to them. Sometimes you find that is not easy for a client to get used to a person visiting them. It can take you a year to visit a client but she/he will tell you his/her problems or illness after a long time. So our organization keeps on motivating us to strengthen our hearts to help our community…."

Dethapelo, Female, 37

3.4.3.1 Monetary support

Some of the participants in the study reported that when they were first hired they were informed that they would receive monetary support. However, for a third of the participants,

these stipends never materialised or were inconsistently received. As much as they all reiterated that they were volunteering, they also noted that a stipend was part of their package, and wondered why they received the stipend so inconsistently. According to the participants these inconsistencies were never explained to them by anyone, but rather, their organization would simply tell them to be patient and continue doing their work. Some at follow up interviews had left the organization and reported that it was due to lack of monetary incentives.

"…Actually, I do not understand their procedure because there are some months where we used to receive R1000 (US$125) and I don't know what happened those months. We receive R500 (US$63) at some points we earn nothing. We have been waiting for five months without earning any money…"

Noria, Female, 35

"…I mean in terms of stipend because now we are running to the third year without getting any money but we are still doing our work…"

Thapelo, Male, 36

The participants emphasised the need for monetary incentives to help them survive and care for themselves as well as their families. For the two male participants this was particularly reiterated as they explained how difficult it was being a bread winner and expected to provide for the family. Hoping for many years that he would be given a permanent job that would help him go live with his family, one of the participants, Thapelo gave up that hope and finally made up his mind that he would leave the organization.

"…I was a volunteer at [name of organization]. I used to get a stipend of R500 (US$63) but eventually it stopped. I didn't understand why I had stopped receiving it. As a result, I suffered and I couldn't buy anything for myself. Every time I asked them they told me that

there was no more money. Even when I asked about money just recently they told me that it would be better if I left their organization in [name of place]…"

Thapelo, Male, 36

3.4.4 Direct and indirect impact of government support

Many participants, together with their organizations, sought to foster networks beyond just their organisation, with the government and other organisations, which they felt could contribute positively towards making their work a success. However, they felt that the government was not paying much attention to home based care organizations and their work, and was at fault for leaving their patients with no food or other basic commodities. They wished government would better support them – directly (with stipends) and indirectly (through extending welfare to communities and individual patients) - to better perform their daily duties. When received by patients, social grants proved to be useful in facilitating participants' work by reducing the burden of care, such that community health workers would quickly discharge patients from their registers as they would be receiving tangible social support. In other words, they were able to buy food and other necessary commodities for themselves as well as their families. Jennifer, one of the participants in her forties, reported for example that those who receive grants were no longer visited. "*...We discharge them because they receive a grant..."* However, Social grants were not the norm in the community and participants' narratives revealed a need for a more effective social grants system, which would affect positively their communities because most of the times participants had to deal with poor households that need food:

"...Like I said in the beginning if only we had food we could give them, if only social services could distribute all food parcels to everyone because my clients disability grant has been cut off..." *Dorcus, Female, 27*

Olga reported government departments do not always respond positively towards the needs of their patient, a source of frustration for hers. This ultimately strains patients who are not receiving enough grant support to sustain their families.

"...Some are staying in a family where the grandmother does not have an identity document to receive an old age grant and we have tried to go to home affairs and to meet with the community civics, but still there is no resolution. In that family, they were surviving with R250, a child support of one of the grand children..."

Olga, Female, 30

Clinics and hospitals played an important role of support for participants in their work. Clinics referred clients to the community health workers mainly for maintaining adherence to chronic treatment and health follow-up. *"...Immediately in the clinic there is a client that needs to be taken care of the nurse will inform me on what to do for that particular client…"*

Prince, Male, 44

Participants also spoke of themselves referring patients, especially those that they found through door-to-door visits, to the clinic or hospital. *"...If we are unable to help a client we always refer to nearest hospital…"Tumelo, Female, 32.* A healthy referral system, according to the participants, seemed to be in existence between the facilities and community health workers.

Referring patients to other non-profit organizations (NPOs) and or social services was another way participants received support for their work and patients they served.

"…Yes and they know that I am working as a community care worker. They are able to tell me when they have problems and I do help them when I can. If I could not make it, I refer them to the relevant people…" *Dethapelo, Female, 37*

"…When we find clients in the field who need special care such as bathing, we referred the patients to the nearby organization …"

Doreen, Female, 28

3.4.5 Altruistic motives

The participants, like many of the community members, reported struggling with lack of money, food and other basic commodities. Yet, they felt pressured and under obligation to assist and give to their patients so that they would be able to take their treatment.

"…I look at the situation of the family like Agnes as I was talking about it. She is a single parent and she is not getting any type of grant. Even her child is not getting grants either. I look at their diet and how they eat and when I see a problem I go to the social worker to explain that I have a client and they do not have food. I also go to the clinic to explain this issue to Matron [name of person] that one of my clients does not have food and she advised me to rush to the social worker and I didn't check with them if they get any food for this week. The social worker has promised me that she will supply my client Agnes with food on a monthly basis…"

Gloria, Female, 60

However they were also situations where participants felt unable to assist beyond offering psychological support and providing their daily duties.

"...We don't have money or resources to help our patients. All we do is to greet and cannot help those who need food..." *Thembi, Female, 40*

3.5 What we do not do and why

While participants spoke about how they performed certain duties, some also admitted they struggled at times and did not do everything that they were supposed to do, revealing pressures and challenges that "forced" them to fall short in their work in the communities.

3.5.1Inadequate skills

A lack of proper training was identified by many, who felt that this restricted their scope of practice. Participants reported that if they did not have the particular skills a patient needed, the patient 'lost out', and therefore they had to inform their coordinators if they had such a problem.

"…I take it (the problem) to the coordinator and they will decide on what to do because I will not be able to help in such situations…"

Tintswalo, Female, 62

3.5.2 Limited resources

Without resources, many community health workers noted that they could not perform their duties adequately. Tumelo, who had been volunteering for about two years and was in her 30s, reported how difficult it was working in a resource-poor setting.

"…We also do homes visits; we don't clean our patient's homes because we don't have cleaning equipment and disinfectants to use…" *Tumelo, Female, 32*

Limited resources extended to some participants having to use what they reported as 'alternative' materials to assist in cleaning or bathing their bed ridden patients.

"... [Instead of gloves]We just use plastics for bread [bread packets] while waiting for them to give us the kit. You find that they say there is no money to buy the kit [the HBC kit contains the gloves]…" *Jennifer, Female, 43*

Some felt they were working as individuals rather than working for an organization.

"…They don't show any support because if they did there would be something that we take with us to our fieldwork. Some other home base care organizations are able to give their patients food parcels…" *Jennifer, Female, 43*

3.5.3 Attrition of community health workers

Being unable to retain community health workers, who often left the organizations, was identified as a barrier to teamwork and the standard pairing approach to home visits. Working in teams assisted participants with their work, as they could help each other, for example, with the heavy task of washing and lifting bed-ridden patients, as well as guarding their own safety within the homes of community members. Additionally, all of the participants reported officially having to work in teams of twos and sometimes threes when out in the community as part of their conditions of service, although this was not always practical.

"…We work in pairs, but now I work on my own because the lady I used to work with left the organization…" *Phumzile, Female, 22*

Some participants, if they were not with a teammate, would not be permitted to enter a home of a patient due to organisational policy. This curtailed their scope of work if a teammate left, although this did not always stop practices that violated this policy. Tintswalo, like others, reported how after finding a patient through door to door and working alone, although against policy, she would teach the primary care givers on how to take care of the patient.

"…The other thing is that it is against the 'law' [policy] for me to be in the house alone and talk to the people who will be with the sick person at home…"

Tintswalo, Female, 62

Participants reported also the need to guard against patients who could potentially violate their privacy while trying to perform their daily tasks. This brought about fear of sometimes not knowing how to handle the situation. However working in teams would make this challenge easier to tackle.

"…At some point you find that it is difficult to do your work that because he [the patient] used to tell me that he is looking for a wife. Hence you find that at some point, I am very much scared to enter his house alone…"

Noria, Female, 35

3.5.4Use of traditional medicine

The use of traditional medicine within the community was reportedly frequent. It was common practice for participants to see their patients visit other healers before seeking health care from the formal health care system. They reported discouraging their patients from visiting these healers and using their medicine, especially as they were not sure how it worked in their body system.

"...I had a problem with a male TB patient. He kept on shouting at his mother because he did not want to go to the clinic; he wanted to go to traditional healers. So I kept visiting him and advising to go to the clinic and not traditional healers. When he got angry I would leave him and go back the following day. One day he asked me to accompany him to the clinic and he got tested..." *Dethapelo, Female, 37*

3.5.5 Gender Issues

Being male or female was reported by one of the male participants as affecting the performance of daily duties. He reported that as a man, he felt unable to perform the full range of services expected - for example bathing female patients in a community where the

cultural norm was that washing and bathing of women was done by women. The services that he was able to render were mainly related to psycho-social support and assistance with physical labour. He would have to draw on a female primary care giver, neighbour or family friend to assist with the "woman's work".

"...I just call her friends to help. And I provide them with gloves to clean to her. No I only wash that wound she has..." *Thapelo, Male, 36*

In contrast, the other male participant interviewed stated that care giving was a job like any other, that any individual could be a care giver whether male or female. He reiterated that care giving could be compared to nursing where males and females could become nurses and perform their duties well.

"...I don't see any difference whether you are a man or woman. It's just like a female and male nurse. They both do the same job. If it's to bathe a patient they will both do it. I also bathe patients and sweep the yard if I find that they are living alone. If the patient was in a bad condition I know I have to go clean their house, wash the dishes, make a fire and cook for them..." *Prince, Male, 44*

CHAPTER FOUR

Discussion

4. 1 Introduction

In policy reforms aimed at reengineering primary health care, community health workers are identified as a central cadre for providing primary health care to all, especially for those living in rural and marginalised areas, where health resources are less available to communities. The aim of the study was to explore how the preparation and support processes for community health workers influences their role in delivery of home-based care services, particularly in a rural context such as the Bushbuckridge sub-district.

The results of this explorative study provide insights into the importance of identity amongst community health workers, how they feel about themselves and perceive the state and society to see them, as well as how this influences their provision of services for patients within their communities.

Many women – whether community health workers or not - within communities are reported to spend their time and resources assisting community members with different health problems (Kironde and Klaasen, 2002, Johnson and Khanna, 2004, Akintola, 2008, Ama and Seloilwe, 2010). Some feminists argue that this continually drags women into poverty as they are not rewarded – financially and in other ways - for their care work that they perform (Kang'the, 2009, Makina, 2009). While many of the community health workers in this study struggled to find alternative employment, many felt that working as a community health worker may one day lead to 'proper' employment (Akintola, 2008, Rodlach, 2009). Makina (2009) however states that because care work is wide-ranging from direct care which includes domestic tasks to looking after those intense and special needs including young children it should be then considered work in its own right. Some of the community health

workers in the study reiterated working hard performing all the important tasks for the patients with little appreciation and support for the work that they did. While some confessed sometimes how difficult it was for them to continue performing the tasks efficiently with very little support, thus they cut back on the scope of services they offered to their patients.

The work of community health workers calls upon the resources, skills, time, energy and funds of communities and governments in order for programs to be effective and efficient. It is also understood that health is the outcome of the overall social and economic development of the community and that, no single entity can meet all the requirements and challenges (NDoH, 2001). Community health workers highlight the need for a collaborative effort if they are to work effectively as mediators or agents between the state, community and organization they volunteer in.

4.2 Role of identity

It is clear from the narratives of community health workers that identity is not homogenous across the board. Different situations contributed to the way community health workers prepared and are supported for their work for example life experience, sex, funding of the organization in which they work and not particularly the years of services in this particular study. Understanding the context of community health workers would assist in directing support for this cadre in ways that suit them. For many community members their community is not but a geographic place for them to live but rather a closely knitted area with personal and inclusive relationships. Living together in such circumstances means knowing your neighbours and understanding many of their needs, as in many circumstances many go through similar challenges. Identifying needs of community health workers according to their identity to an extent would assist them to work to their best ability and impact positive change on health outcomes at the community level.

4.3 Role of the state

The state plays a huge responsibility in enabling the work of home caring as it is responsible for the provision of public health care. In South Africa's new policy reforms around community health workers, it is envisaged that the state will take care of community health workers' needs. This will be done directly through financial and non-monetary incentives, job descriptions and training, and indirectly, by providing links to departments that assist their patients with, for example grants, food parcels, housing and other necessities.

Community health workers cannot work in isolation, they need to work collectively with other players in order for their work to be efficient as well as fulfil their duties (NDoH, 2009). Studies show that the community health worker role is broader than health promotion but rather they are a voice for communities (Rodlach, 2009, Akintola, 2010, Russel and Schneider, 2000, Schneider et al., 2008). Community health workers are a means of bringing communities closer to the services that they need, they do not only assist sick people in the community but also link community members with other services that they may need. Old age, child, foster, disability grants are some of the grants available to communities and a social worker needs to be connected to these communities by the community health workers so they are able to receive this assistance from the state. A healthy referral system therefore needs to be in place to assist this type of work, as community health workers continually need to refer community members to various departments. In this, the state needs to take an active role in supporting their work through the relationships formed between the community health worker and the formal health care system i.e. hospitals, clinics, social development, the police, and other essential departments, and acknowledge that the support they need comes not only from one person, organisation, facility or department, but different entities working together towards a common goal.

4.3.1 Indirect service of the state

The state is responsible for supporting the social service needs of underprivileged communities, including the provision of social grants, housing, and related-livelihood services (Samson et al., 2002). Community health workers in this study were identified as brokers, and this related to them linking different types of resources for the community. Food parcels were the main concern as patients were often too poor to afford food. Housing was also an issue as patients or community members did not have proper housing to live in. Being able to supply food, medication and other basic supplies received from the state made their experience of home caring worthwhile. Similarly in a study done in Kenya community health workers reported that when their patients received basic needs it made their experiences of caring for them bearable (Johnson and Khanna, 2004), rather than having patients complaining of hunger, or lack of other basic services and being unable to assist. This highlights the importance of a proactive state in supporting community health work and responding to the needs of impoverished and vulnerable communities.

Participants reported that patients have high expectations of community health workers, who were in many instances struggling with the harsh condition of poverty themselves. Rural areas have the highest poverty rates in South Africa (Hassim et al., 2007) and working with patients without food is difficult for community health workers. A study in Botswana also revealed that many community health workers there assist their patients out of their own pockets yet they also are affected by poverty (Kang'ethe, 2009), and this is likely to drag them deeper into poverty. Ultimately, without a proactive welfare state, home caring could simply become a burden rather than volunteer work done for altruistic motives (Akintola, 2008). In a highly inequitable society, even with a proactive welfare state like that in South Africa, this is a risk, as this study reveals.

If community health workers are to play a meaningful role in the revitalisation of primary health care, how they are supported will need critical examination (Pillay and Barron, 2011). The lack of resources to fulfil their duties, for example lack of gloves when washing bed-ridden patients, is one of the areas that needs strengthening, for the participants in the current study as well as elsewhere. Studies of community health work in parts of South Africa, Zimbabwe and Botswana have shown how difficult it is to work without the necessary equipment (Rodlach, 2009, Goudie, 2011, Majumdar and Mazaleni, Kang'ethe, 2009). The lack of such resources does not only threaten community health workers (through exposure to disease (Mills, 2011) but also, in the long run, could affect the health of their own families (Rodlach, 2009, Akintola, 2010, Kang'ethe, 2009, Agbonyitor, 2009, Gitomer, 2010). This is because the community health workers may be exposed to these diseases and then spread them to their own families. In South Africa, every community health worker across the board is expected to carry a home based care kit of basic supplies and essentials (Goudie, 2011) but, as this study shows, for many this is merely a dream. Literature supports that if community health workers are adequately prepared for their work they can positively shape an accessible, affordable and effective health system for populations, however this needs adequate resources and support (Gilson et al., 1989). Therefore the equal distribution of these resources by the state to home based care organizations is very important.

4.3.2 Direct services of the state

Community health workers in this study, as in previous studies and elsewhere (Schneider et al., 2008), reported a lack of regular remuneration. This was de-motivating as they reiterated the need to eat, wash their clothes and be presentable when working. However, remuneration of community health workers has brought about lots of international and local debate, where some authors have argued that monetary remuneration of such programs could have negative effects, as volunteering allows people to perform on a more willing basis (Lehmann and

Sanders, 2007). Studies have also noted that other incentives could be used rather than monetary remuneration, that there is no absolute package that could keep community health workers motivated (Bhattacharyya et al., 2001). Ethiopia is an example of a country where community health workers are given other forms of material incentives, for example uniforms, hats. T-shirts, badges with logos, umbrellas, shoes that are greatly appreciated by the community health workers and this keeps them motivated (Yared, 2009). It is important to understand the context as well as needs of a particular group to be able to determine the types of incentives to be offered. Central to the narratives in the current study, monetary remuneration was identified as important for their survival. However this was not the driving force for their work and alternative incentives such as transport, food and continual training seemed to be of great value as well. According to Pillay and Barron (2011) for the work of community health workers to be worthwhile in the new policy, the current low levels of remuneration must be addressed. "Ideally, all workers providing essential services through full time employment should become part of the formal public health care system" (Pillay and Barron, 2011). The policy acknowledges this and states that community health workers will be paid a decent and regular salary, with all 'dry seasons' eliminated (DOH/DSD, 2009, Barron et al., 2010). In a recent study in South Africa exploring policy development, one of the policy makers interviewed suggested that the position the state has kept in recent years with community health workers may be linked to a cheaper way of getting the job done because they would not have to provide full benefits for the employees (Daniels et al., 2012). This new policy tries to address this as a way of strengthening the health system.

However there is still a policy gap as not all of the community health workers currently in the system will be absorbed into this new initiative. The policy suggests that the rest of this cadre (which seems to be identified by merely a different name – as home-based carers), will

continue to volunteer under non-governmental organizations/ non-profit organization (NGO/NPO) (Barron et al., 2010), with the risk that the cycle of challenges re-start for them.

Receiving certificates following training was reported to be a source of support and motivation for many of the community health workers interviewed in the current study. Yet also important was the 'informal' training community health workers received before starting out in care work more formally. Many reported taking care of a sick person or doing something 'caring' for the community. This seemed an equally important form of preparation for their work.

The support received from certificates is evidence of added qualification that would be useful while looking for better job opportunities (Kironde and Klaasen, 2002). In the current study, community health workers who had not received their certificates showed signs of unhappiness and were trying hard to make sure that their supervisors would make these certificates available to them. Although being a community health worker was part of who they identified themselves as, giving a sense of identity and professional status that was important in their communities; this status was also related to career development and applying for better jobs. Having (recognised) training empowered them to make informed choices about their career possibilities as well as for their patients as they had the knowledge to make these decisions.

However, at a health system level, training community health workers could ultimately mean losing them to another sector, presenting 'a double edged sword' if the system fails to retain this group due to lack of incentives but uses state resources to train them. Given the high unemployment rates in the area as well as other rural areas (Statistics SA, 2009); increased training would thereby improve their labour market opportunity and increase this risk.

Yet, this study also shows that the acknowlegement of the community health worker proffessional role in itself is a motivation source. For participants, this proffesional status was elavated by the knowledge that they received from training and could be used as a retention strategy, when coupled with other incentives, including remuneration. The state is responsible for most of the training activities that take place amongst community health workers although some nongovernmental organizations (NGOs) trained their community health workers. The new policy in the re-engineering of PHC suggests an agreed upon standard training that will be used for all community health workers, by doing a gap analysis and identifying priorities for training and deployment (Pillay and Barron, 2010). This would strengthen the work that community health works perform within communities and make their work more efficient.

4.4 Role of the community

The acceptance of community programs needs communities to buy into and understand such programs. It is therefore important that communities are given full information so that this can help them to understand home caring and avoid unwanted interpretations and expectations that hamper the work of community health workers. Trust and confidentiality are big issues amongst communities. Some communities and individuals do not trust the community health workers working in their areas. This might be, as participants in this study suggested, because community health workers are identified as 'markers of HIV' and community members do not want to be associated with the stigma related to HIV/AIDS. In a study in KwaZulu Natal patients shared similar feelings about the lack of trust and confidentiality for community health workers in their work (Horwood, 2012). This, they reported, was because community health workers do not maintain confidentiality and tell other community members about the diseases that their patients are suffering from, which in most cases was HIV/AIDS (Akintola, 2008). Patients then refused to be cared for by this cadre in the fear of stigmatization of the disease. They also reported that some of the

community health workers disclose the status of patients to their colleagues or other people within the community (Horwood, 2012). The policy guide and training provided in the new policy should improve the way community health workers deal with issues of confidentiality within the community.

Support from community members in the work of home based care can be increased when community members value the knowledge community health workers possess. Due to the health education that is part of the daily duties, in schools, households and in the community in general, community members begin to trust and give respect to the community health workers. Further, if community health workers prove to communities their trustworthiness as well as efficiency in other service delivery, then community members will support the work that they do. When the community has full support for community health workers then these programs are supported and they can work (Prasad and Muraleedhara, 2007) and can bring about the necessary change that is needed. Like one of the community health workers interviewed in the current study said, the community will begin to see them as 'doctors', showing that they would be supporting the work that they are doing. This is because the status of being a doctor among communities is highly respected. They are seen as people with knowledge and are always able to help with health related problems at all times. Yet it is also important not romanticise the role of community health workers and who they can be in the field of home caring.

Culture is a contested concept, and literature often deals with culture in relation to identity, closely linked to customs, beliefs and traditions (Gilbert et al., 2010). Women in many different settings, South Africa included, have been identified as care givers within the home (Makina, 2009, Akintola, 2006, Rodlach, 2009, Lund and Budlender, 2009).Society has encouraged women to provide care for their families and the community without payment as part of a 'care economy' (Mills, 2011). The traditions and customs in these communities have

shaped these societies this way. However, the experience of home caring should not be a burden for the women, including those who sometimes carry out tasks for their male counterparts as in the current study. A study looking at policy development surrounding community health workers in South Africa reported that sometimes due to lack of employment women offer to fill in the gap giving away their time for a small amount of remuneration which in return would limit their education as well as career development (Daniels et al., 2012). Further they reported that there is an Office of the Gender Focal Point which should participate in developing community health worker policy to protect the gender issues facing this cadre. However, this office was limited in its power and capacity to influence policy (Daniels et al., 2012) and suggest that gender is something to be re-thought and critically considered in light of the new reforms.

The use of traditional medicine among many communities in South Africa is common practice. Individuals interpret and understand illness in terms of their culture, it shapes the ways in which people make sense of the causes and manifestation of health and disease (Gilbert et al., 2010). Community health workers have to deal with patients who practice patterns of medical pluralism notably their HIV/AIDS and TB patients. (Moshabela et al., 2010) reported in their study how the use of different treatment methods delays access to health care. Community health workers, as part of their duties, are meant to encourage community members to get tested for HIV and TB through their health education programs (Languza et al., 2011). The presence of community health workers has shown to increase community involvement in HIV testing and counselling in many settings and therefore can be used in many parts of community services if supported in all aspects. However, community perceptions of HIV/AIDS will need to change before even community health workers begin to pioneer ideas of behaviour change.

4.5 Role of the organization

In this study, the organizations, the community health workers were affiliated to played an important role in impacting on their daily duties. Respondents reiterated the emotional, sometimes material and financial support that was received from the organizations. This helped them to cope with the day to day challenges of home caring. Similarly a study done in KwaZulu Natal showed that for those community health workers who received support from the organization their experience of caring for their patients was bearable (Akintola, 2008). Sharing their day to day challenges with others within their group assisted their work and left them feeling they could continue despite the challenges. A supportive environment may allow volunteers to cope better with the stresses that they face each day while in the field. Therefore, a guide for organizations that improves coping strategies, such as debriefing meetings for community health workers, could be useful, in helping them deal with their day to day challenges.

Organizational policy needs to guide the work of community health workers in all activities and services they provide. Some authors have noted that activity rates of community health workers in national programs may be low especially when there is less support and supervision for their work (Gilson et al., 1989). Therefore there is a need for organizations to seriously consider the supervision of their community health worker teams, although community health workers in different studies claim to give their priority to patients and that they do the work efficiently for them (Languza et al., 2011, Akintola, 2006, Rodlach, 2010, (Kironde and Klaasen, 2002). Standardization throughout organizations may assist community health workers and organizations to work more efficiently. In circumstances where supervision and support are weak it is difficult to guarantee that a high quality of care is maintained.

The discussion document on the re-engineering of primary health care suggests hiring community health workers on contract or on permanent basis (Barron et al., 2010). While one of these ways will be used both the ideas will leave many unemployed as a certain number will be hired (Goudie, 2011). This ultimately means not everyone will be able to become a community health worker, potentially filtering away the people who may have started these organizations because they saw a need within the community (Gitomer, 2010), and employ those the system deems as 'qualified'. There is need for the state, community and organizations together to play an active role in the development and operation of community health work. Training and counselling of community health workers on how to cope with their work; and lack of resources is essential support.

4.6 Limitations

The researcher did not carry out all interviews and the use of three different research assistants to carry out the interviews may have contributed to possible errors in the different ways participants answered the questions or in the translation of the interviews. All the research assistants were trained to do a verbatim translation of the questions in the interview guide and regular team debriefings sought to maintain and articulate the focus of the study.

Social desirability among participants interviewed posed as a limitation in the study. Participants always present themselves in the best possible light this leads to them reporting what they perceive as good or impressive (Fisher, 1993). Research assistants were trained in asking indirect question as well as probing techniques to ensure that participants do not answer questions in a manner that would present them in the best possible light, but rather a true reflection of their experiences.

The use of secondary data in the research was another limitation. The data was already collected therefore no follow up questions could be generated for the proposed research

question. Also questions relating to the NPO itself could have made the data richer; however this is a gap for further research on the subject.

CHAPTER FIVE

5.1 Conclusion

Looking at community health work in developing countries more than two decades ago, Gilson and colleagues (1989) identified that a lack of appropriate skills and practice could impact negatively on this cadre of health workers and their work, making it difficult to provide good quality care. The current study similarly confirms that a lack of skills and practice, amongst other issues, impacts negatively on the way community health workers in a rural North-East South Africa care for their patients. Beyond compromising the quality of care delivered, feeling ill-prepared and unsupported, or, conversely, skilled and well-trained, is an important part of the identity attached to being a "community health worker" and caring for patients in the home environment. Understanding this 'identity' would be useful for planning purposes as well as policy formation for this cadre.

Training amongst community health workers can provide useful skills to help them provide quality care. Training can also support and boost their confidence as community health workers can be an incentive in its own right. This is because training comes with knowledge, knowing what ordinary community members may not know about, for example knowledge on diseases such as HIV/AIDS, TB, diabetes and nursing patients. However, preparation from the perspective of community health workers in this study is not merely the training they receive at the outset, when they 'sign up' in the organizations where they volunteer but rather, is a process that begins long before actually joining these organisations. As many noted, a certain way of life and form of socialization has prepared them for the work that they do. Being a 'community insider' before becoming a 'community outsider' or 'broker' once

appointed as a community health worker, has, in this narrative, allowed them to experience a life of helping others, although in an informal way. Informal care-giving taught participants to look after their neighbours, parents, sisters, brother, aunts and others, thereby training them to become community health workers later on in their lives. Once formal volunteers in home based organizations, however, the participants acknowledged that they needed both formal training and on-going, broad-ranging support that takes into account the lack of resources and difficult circumstances of their work. This means emotional, physical and financial support to get their work done is essential at all times.

South Africa's current re-engineering of PHC using community health workers as a central element of reform does, in some ways, acknowledge the importance of preparation and support for this cadre. According to Pillay and Barron (2010), these reforms acknowledge a need to consolidate and standardise basic training as well as provide on-going training of community health workers, through agreed upon national appropriate competencies, skills and qualifications within the programme. Yet, this vision can be taken further, to include the provision of psycho-social support and financial resources as part of the up skilling of this cadre.

The reorganizing of PHC also hopes to move away from a system with multiple community health workers working in parallel, fragmented and unstable work situation, to a system which is consolidated and stable. At the same time, this vision of community health workers is only possible if it is positioned within a bigger health care system that seeks to strengthen the supply, management and deployment of human resources for health. "No single person, programme or department can address the complex challenges faced within communities, hence this value emphasises the need to collective action based on interdependence" (DoH/DSD, 2009). If health outcomes are to be improved, it is important that this massive investment in training, supporting and employment of the health workforce, including

community health workers, is well planned, appropriately targeted and properly managed (HRH Strategy for the Health Sector: 2012/13-2016/17).

5.2 Recommendations

Training and capacity building

The health system needs to acknowledge the perspective of community health workers taking care of the sick, doing household chores for the community as a way of training, in addition to the accredited training they would receive when they have formally started in home based care. This type of training, the current study has suggested contributes to the identity of community health workers and somehow reflects on the work and activities that they perform.

Consistent, on-going training for community health workers throughout their working period as care workers is very important. This will keep their knowledge up to date and provide any new information they need to know about their work. This will also boost their morale and motivate them in the work that they are doing. The researcher recommends a more interdependent framework be used in order for both the receivers and providers of care gain a positive experience of home based care. This interdependent framework should be part of policy to have all stakeholders involved in decisions and work relating to caring. The working conditions among community health workers has to be highly improved with better support of equipment for their work as well as financial support. This is important due to the delicate tasks some have to perform such as washing bedridden patients.

Self-reported narratives of the type on which this report is based can reflect a lack of awareness among participants to view themselves critically in relation to their work. This in itself might be a barrier in the work that they do. Therefore as one suggested way forward,

future training for community health workers might include dialogue with patients, clinics, NGOs and other stakeholders involved in the care work that they do.

Policy reforms for Community Health Workers

Policy reforms that are currently taking place should organize community health workers in a way that they have specialised training to cater for their particular patients, instead of the more generic training that is 'supposed' to be given to all of them. This will assist community health workers cope with the rapid medical progress with resultant changes to treatment protocols that occur as well as continue to reinforce the skills and knowledge that CHWs have acquired already.

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APPENDIX A

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

Community Care Worker: Interview Guide

1. What is your background? Tell us about yourself?

2. How did you get started in HBC? (When/Date?) How did you prepare yourself? Why did you join _____ organization?

3. How did they organization help prepare you? (Trainings?)

4. According to your organization what services are you supposed to provide?

5. How does your organization support you? And your work? (E.g., meetings, debriefings, skill development)

6. How many clients do you have? What types of clients do you have?

7. What does your typical day look like?

8. How do you find these clients? What do you do for these clients? (Process)

For questions 9-16 please ask the question twice for each of the clients selected.

9. Tell us about _____ (client 1/ client2)? (Conditions, health needs)

10. How did you find _____ (client 1/ client 2) as a client? (Process)

11. What do you do for _____ (client 1/client 2)? (Number of visits, frequency, services provided)

12. How is the ____ (client1/client 2) coping with the illness? What is their progress?

13. How do you work with _____ (client 1/client 2)?

14. Are there services you would like to provide to _____ (client 1/client 2) that you are not able to? Why? What would help?

15. How do you work with _____ (client 1's PCG/ client 2's PCG)?

16. What do you do for _____ (client 1's PCG/ client 2's PCG)? 15

17. After all the services that you have provided what, when and how do you report to your organization?

18. What is your role in the community as a whole? Do you think this is enough? If not, what other role could you be playing?

19. How has your work as a carer affected your life?

20. What could improve your work as a carer?

Appendix B

RADAR
RURAL AIDS & DEVELOPMENT
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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 organisation, 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 of the 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, Dr Mosa Moshabela, at 013 795 5076 or 0834943089.

Thank you for your time.

APPENDIX C

INFORMED CONSENT

I hereby confirm that I have been informed by the interviewer, _____, about the nature, conduct, benefits and risks of clinical study.

I have also received, read and understood the above written information (Participant Information Leaflet and Informed Consent) regarding the clinical study.

I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and profession will be anonymously processed into a study report.

In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by RADAR

I may, at any stage, without prejudice, withdraw my consent and participation in the study.

I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

PARTICIPANT:

Printed Name Signature Date and Time

I, _____, herewith confirm that the above participant has been fully informed about the nature, conduct and precautions of the above study.

INTERVIEWER:

Printed Name **Signature** **Date and Time**

APPENDIX D:

INFORMED CONSENT FOR VOICE-RECORDING

I hereby confirm that I have been informed by the Interviewer, _____, that the information I provide during the interview will be voice-recorded.

I am also aware that the voice-recording will be done using a small and silent digital voice-recording machine.

I have also been informed that the information recorded will be stored electronically and confidentially by RADAR.

I am aware that the recording is done for research purposes only, and that the recording will not be made available to anyone else besides the research team and not for any other purpose besides research.

In view of the research requirements, I agree that the information recorded be stored electronically using a computerised system by RADAR.

I may, at any stage, without prejudice, withdraw my consent to the recording of the interview.

I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to have the interview recorded.

PARTICIPANT:

Printed Name Signature Date and Time

I, _____, herewith confirm that the above participant has been fully informed about the nature of the voice-recording for the study.

INTERVIEWER:

Printed Name **Signature** **Date and Time**