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**“She is my teacher and if it was not for her I would be
dead”: Exploration of rural South African
Community Health Workers’ informational and
mediating roles in the home**

By

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Declaration

I, Rose Zulliger, student number ZLLROS001, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any university.

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Executive Summary

Community Health Workers (CHWs) play a central role in the provision of health services within the South African context by providing preventative, promotive, curative, palliative, and mediation services within the home. This role has recently been reconceptualised and revitalised with greater emphasis placed on CHW Information, Education and Communication (IEC) services. Despite the reprioritisation of these services, there is little evidence from the African context on CHW capacity to specifically meet the IEC needs in the home. Exploration is needed of the foundation of this role change and of CHWs' de facto provision of IEC services on the ground. This thesis seeks to fill the gap in the literature by exploring CHW IEC roles through: a protocol for the Health Information in the Home (HIH) study of the quality of IEC services by Community Care Workers; a structured literature review of the current state of the evidence and a journal manuscript based on the HIH study findings.

The HIH study protocol is comprised of the proposal which was accepted by the University of Cape Town (UCT) Human Research Ethics Committee (HREC) for the HIH study. It describes study background and methods. Semi-structured, qualitative interviews with CHWs, their clients and the clients' primary caregivers (PCGs) were proposed. The thesis author's background working with a home-based care organisation in the study site from 2007-9 is also highlighted.

The structured review of relevant literature addresses the question, *What is the context for the evolution of CHWs as purveyors of various forms of Information, Education and Communication (IEC) in the home and what evidence has influenced this evolution?* The extensive history of community health worker use around the world and in South Africa is described. CHWs' roles have evolved from serving as catalysts of change to providers of curative and palliative services who filled gaps left by the over-stretched health system. Their role now emphasises preventative and promotive services, including IEC, in order to facilitate therapeutic alliance and to reduce the burden of disease. There is, however, insufficient scholarly evidence from Africa on the provision of IEC services in the home to adequately inform policy and practice.

The journal manuscript seeks to add to the body of literature by using qualitative methods to explore the need for and the de facto contribution of CHW IEC services in the home. Semi-

structured interviews were conducted with 17 CHWs, along with 33 of their clients and 30 of the clients' primary caregivers (PCGs), to allow for data source triangulation (n=80). 22 follow-up interviews were conducted with these participants to further investigate emergent themes. CHWs draw on both formal and informal training to provide a broad range of IEC services in the home, including facilitation of intra-household communication. This is done through CHW adaptation of general and disease-specific health messages to their local context in order to facilitate cultural acceptability and understanding. CHWs' role as community members with an understanding of the formal health sector allows them to bridge the worldviews of the home and the formal health sector and enhance cultural access. Their role could, however, be compromised by a lack of appropriate training and, ironically, by the increasing formalisation of other CHW roles. The manuscript emphasises the need to support the CHWs' pivotal role as the interface of informal and formal healthcare.

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PART A: RESEARCH PROTOCOL

Health Information in the Home (HIH): Appropriateness and Quality of Community Care Workers' Health Information Provision in a Rural South African Sub-District

May 2010

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*Study is part of the broader Care in the Home in Rural South Africa Study which has Dr. Mosa Moshabela as Study Leader. Rose Zulliger is Primary Investigator for the HIH sub-analysis.

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List of Abbreviations

CHRSA	Care in the Home in Rural South Africa Study
CHW	Community Health Worker
HBC	Home-Based Care
HIH	Health Information in the Home Study
HREC	Human Research Ethics Committee
IEC	Information, Education, and Communication
NGO	Non-Governmental Organisation
PCG	Primary Caregiver
PLWHA	People Living with HIV/AIDS
UCT	University of Cape Town

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Definition of terms

Home Based Care (HBC) Non-Governmental Organisation (NGO)- an organisation which employs community health workers to provide a variety of health-related services in the home.

Community Health Worker (CHW) - a community member who is affiliated with a HBC NGO, regardless of receipt of remuneration, *at the time of sampling frame completion*. The term is used interchangeably in the proposal with “community care worker” which was the term used by the South African Departments of Health and Social Development when the proposal was written in May 2010. The Department of Health has referred to these workers as CHWs since late 2010.

Primary Caregiver (PCG) - a family member or neighbour who has been identified by the client as being the person who provides the majority of care for the client, but who is not affiliated with an HBC NGO, *at the time of client interview*.

Client- a community member with any illness that has led to visits by a CHW. This illness may be chronic or non-chronic, but the client must be receiving care *at the time of sampling frame completion*.

Triad of Care in the Home- the trio of client, PCG and CHW and their relationships with one-another.

Health Information Services- the provision of information on health conditions, on preventative health measures, on how to access services, and on the provision of appropriate care.

Introduction

The South African health systems have been stretched by the HIV/AIDS pandemic and its associated opportunistic infections, and also by the burgeoning level of non-communicable diseases. This has led to an emphasis on “task-shifting” in which community members such as CHWs are allocated to provide community health services (Lehmann et al., 2009). These services include those which promote health within the community through health education, prevention messages and capacity-building on appropriate care for the ill. Given the vital role that CHWs are now expected to play within the overstretched health system, it is imperative to understand the quality of these services provided and whether CHW services adequately meet community needs.

There are numerous case studies of home-based care by CHWs and PCGs, but little evidence exists on the quality of health information provided or on the relationship amongst these care-providers and with recipients in households infected and affected by HIV within Africa. This is a critical gap within the literature. Understanding the quality of health information services provided by CHWs will allow for a contextualisation of CHW experiences and service outcomes. Research with the care providers/ recipients will also allow for triangulation to assess what information is actually provided and how relationships impact upon these services. This will allow researchers and policy makers to identify key areas for intervention to improve the quality of promotive health services provided by CHWs.

The Health Information in the Home: Appropriateness and Quality of Community Care Workers’ Health Information Provision in a Rural South African Sub-District (hereafter referred to as the HIIH Study) seeks to fill some of these gaps in the literature. It will use qualitative methods to explore the health information needs and services of CHWs, PCGs, and clients, along with the inter-relationships which may impact these services. This will be done through semi-structured interviews with CHWs, with their clients, and with the clients’ PCGs, representing the three different constituents of the triad of care in the home. The study will be conducted within the rural sub-district of Bushbuckridge, Mpumalanga as the experiences of rural HBC in South Africa is insufficiently researched. Bushbuckridge is a designated poverty node which has a high rate of HIV along with an extensive HBC network. The Principal Investigator spent 2 ½ years working in this area with HBC and, therefore, is well-placed to perform this research project.

The HIH study is a sub-analysis of qualitative data from the Care in the Home in Rural South Africa study (hereafter referred to as the CHRSA Study). The CHRSA study will utilise mixed methods to determine the quality of care being provided by CHWs affiliated with HBC NGOs in Bushbuckridge. The Study consists of three phases: a situational analysis phase to understand the context in which HBC operates; a qualitative phase of semi-structured interviews with CHWs, PCGs and clients to begin to understand the relations amongst this triad of care and the quality of all forms of care provided; and a quantitative phase to assess the quality of care being provided.

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Study Purpose and Aims and Objectives

Purpose of the Study

The HIH Study will add to the body of literature on Home-Based Care and provide a more thorough understanding of the quality of health information services provided by CHWs. The study will explore what health information needs exist amongst clients and PCGs, will investigate how CHWs view their role as health information providers and will help to understand how the triad of care perceives the quality of health information services in the home provided by CHWs. This study will fill an additional gap within the literature by interviewing all three members of the triad of care in the home and triangulating their experiences. This study will explore health information services in the home and expand it from a static, listed term to a more nuanced, complex and dynamic service.

Overall Aim

Evaluate the appropriateness and quality of in-home health information provision by Community Health Workers in Bushbuckridge, South Africa.

Specific Objectives

1. Assess the self-identified health information needs of PCGs and clients;
2. Assess the nature and extent of information provided by CHWs in homes;
3. Evaluate the degree of fit between CHW health information services and community health information needs;
4. Evaluate the training, communication competencies and sources of health information of CHWs along with their perceived self-efficacy.

Background

Home Based Care Terminology

There is a broad range of terms used in the literature and colloquially in reference to community health workers including “community care workers”, “community caregivers”, “home-based caregivers”, “community based health workers”. These terms refer to community based health workers who are given a limited amount of training to carry out health and welfare services within their own communities. These workers are supported by the health systems, yet held accountable by their own communities (Lehmann & Sanders, 2007; Friedman, 2005; Gilson et al., 1989; Schneider et al., 2008). This paper will use the general term of CHW more specifically to describe the specific cadre that provide home based care work who are affiliated with Non-Governmental Organisations because it is the term that is currently being promoted by the South African Department of Health. CHWs are viewed as workers who supplement the informal and primary caregiving activities often performed by patients’ family and friends (i.e. by PCGs).

Home Based Care

The World Health Organization broadly defines Community HBC (CHBC) as “any form of care given to ill people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities. The goal of CHBC is to provide hope through high-quality and appropriate care that helps ill people and families to maintain their independence and achieve the best possible quality of life” (WHO, 2002). HBC is one more specific cadre of the more encompassing field of community health work. The essential concept of community care work is to empower community members to identify their own needs and to implement their own solutions. CHWs have the capacity to develop and implement innovative solutions to respond creatively to locally identified health needs (Witmer et al., 1995).

CHWs are not a new phenomenon within the world or Africa. Community members have been providing health services for at least 50 years, the most notable of which was the “barefoot doctors” program in China (Lawn et al., 2008). Despite this long history, CHWs only came into prominence as a mechanism for providing services in the early 1980s. This emphasis was related to the introduction of Primary Health Care paradigm in the WHO declaration of Alma Ata (Schneider, et al., 2008). CHWs filled a variety of roles, but were predominantly seen as both

health workers and as community advocates working as catalysts of social change (Lehmann & Sanders, 2007). Interest in CHW programmes, however, began to wane by the late 1980s as programmatic limitations emerged. These challenges included unrealistic expectations of volunteer roles, lack of community ownership, poor programmatic planning, and problems with sustainability and quality maintenance (Gilson et al., 1989). The economic recession and subsequent World Bank-driven policies of structural adjustment further led to the collapse of most large-scale, national programmes (Lehmann & Sanders, 2007). CHW services did not disappear completely, but continued to operate on the periphery of the health services until the emergence of HIV/AIDS.

The services and roles of CHWs who provide HBC have evolved over the past decades and continue to do so in order to meet local contexts. HBC for people living with HIV/AIDS (PLWHAs) first emerged in North America and Europe in order to provide more comprehensive and cost-effective care (Ncama, 2005). The service has now rapidly spread throughout Africa, including South Africa. HIV/AIDS had a profound effect on health services throughout the world and CHWs were seen as a mechanism for mitigating these systemic effects. Home-based care and CHWs were identified as a solution to the shortage of hospital beds, health professionals, and resources, and the difficulty of hospitalisation of patients with long-term, terminal illnesses (DoH, 2001). CHWs came back into prominence as the World Bank promoted task-shifting to alleviate over-stretched health care systems (Schneider, et al., 2008).

The long history of CHWs and increasing “task-shifting” and PLWHA service-provision have further complicated CHW roles and have created a context in which great variety exists throughout the various CHW sectors in South Africa, particularly in regards to HBC services (Naidu, 2005). The history, practices, and definitions of HBC within South Africa will now be discussed to contextualise the current research within the broader practice of HBC in South Africa.

Home Based Care in South Africa

CHWs have a rich and extensive history within South Africa, dating back to the Pholela rural health unit which utilised CHWs as outreach agents in communities as part of early Primary Health Care System efforts (<http://www.kznhealth.gov.za/pholela/history.htm>). CHW programmes in South Africa that provided HBC services were initially started by non-governmental

organisations(NGOs), community-based organisations (CBOs), faith-based organisations (FBOs), and concerned individuals (Cullinan, 2000). In the 1990s the South African state began to financially support the NGOs employment of CHWs (Schneider et al., 2008). These initial efforts at HBC undertaken by the South African state and by countries around the world were described by the WHO as having been ‘unsystematic and needs-based’ (WHO, 2002). This need for a more programmatic and organised approach to care provision led the WHO to develop a framework for the establishment and maintenance of community and home based care (WHO, 2002).

The South African government followed the WHO’s example and released a national guideline for HBC/ Community Based Care in 2001 (SA DoH, 2001). The CHW Policy Framework explicitly states that the preferred model of service delivery is a government- NGO partnership in which the NGOs receive government funds to employ the workers (Schneider et al., 2008). The guidelines propose that the formal sector will be the overarching body responsible for planning and managing HBC and supporting its work. The government sectors directly involved in support for HBC are the Department of Social Development and the Department of Health. The informal sector, such as NGOs, has responsibilities which include operational coordination, direct care, Monitoring and Evaluation, and referrals (DoH, 2001).

HBC Services

The South African Department of Health’s *National Guidelines on HBC* proposes a broad definition of HBC that, like that offered by the WHO. The guidelines classify HBC services as preventative, promotive, therapeutic, rehabilitative, long-term maintenance, and palliative care (SA DoH, 2001). The goal of preventative and promotive health services by CHWs include provision of community health education and interventions which can promote health behaviours and reduce disease transmission (Qukula & Watkins, 2009). The former Minister of Health identified health promotion services as a CHW programmatic “imperative” (SA DoH, 2004). Despite this critical role, little research exists that investigates the implementation or outcomes of HBC promotive health services. Research articles and policy makers list promotive health services in the form of health education/ promotion/ disease prevention as one of many services provided by CHWs. It is taken for granted that these services have substantial impacts upon the communities, but there is little scholarly evidence demonstrating the positive outcomes of these services. There are, however, some negative experiences highlighted in the literature such as that HBC care services

are inhibited by low CHW skill and capacity (Ndaba-Mbata & Seloilwe, 2000; Orner, 2006; Uys, 2002; Harding et al., 2005). This low level of CHW capacity may be linked to deficiencies in CHW training. CHW training varies substantially in standards, durations, and quality and is often not standardized at a national level (Desmond, 2002; Mabude, 2008).

There is some literature that demonstrates the vital role that CHWs can play in provision of services, including health promotion services. One study on Tuberculosis (TB) by Bond and colleagues on the role played by CHWs in providing TB services within the community found that HBC was the second-most cited source of TB information by patients. This study interviewed patients and CHWs, but focused only on TB patients and failed to interview PCGs (Bond et al., 2005). Despite the education provided by HBC organizations, studies in Kenya and Botswana have found that education for PCGs and training in AIDS care remains insufficient (Kange'ethe, 2009; Olenja, 1999) and patients in South Africa were found in a neglected state when admitted into care, highlighting the need for an outreach program to enhance the quality of familial care (Uys, 2003). Odindo (2008) found that in Kenya there were policies and strategies for the training of PCGs by CHWs, but no strategies for monitoring the implementation of the trainings (Odindo, 2008). Successes on health promotion by CHWs have been highlighted in the literature, but exploration of what these health promotion services entail in relation to what community health promotion care needs exist is lacking.

Methodology

The HIH study is a sub-analysis within the parent CHRSA Study. The larger study is a three year study which will utilize a mixed methodology to explore and evaluate the quality of care being provided for clients by community health workers affiliated with HBC organisations and PCGs. The HIH study will specifically analyse the CHRSA qualitative data for health information content.

Study Timeline

Study Procedure	Timelines
1. UCT Ethics Application	May 2010
2. Qualitative Data Collection	May-June 2010
3. Data Analysis and Write-Up	June- Nov 2010
4. Publication Submission	Dec 2010

Study Design

The HIH study will explore health information services within the broader Qualitative Phase data of the CHRSA Study. This phase of the study will consist of in-depth, semi-structured interviews with members of each level of the triad of care in the home: CHWs, clients and PCGs. Some of the interviewees will be interviewed on two separate occasions to allow for follow-up and a more thorough understanding of the care needs and services. Qualitative interviews have been selected as the appropriate method to garner a broad picture of the various information needs and services, particularly given the incomplete understanding of CHW health promotion provided by the literature. The interviews will be semi-structured in order to provide more consistent results between the three interview teams.

Study Setting and Characteristics of Study Population

The study will be conducted in the Bushbuckridge sub-district located within the Ehlanzeni District of Mpumalanga Province. Bushbuckridge stretches alongside the Kruger National Park to the border of Limpopo Province, on an area of approximately 60 km x 40 km. The sub-district has been designated one of the 13 rural nodes of South Africa by the Presidency. The region has also

been denoted as a Presidential Node of Extreme Poverty. The previous homeland is inhabited by a population of about 620 000 people who are primarily Xitsonga- or Sepedi-speaking.

The subdistrict health services are driven by the Department of Health with 3 hospitals, 2 health centres and 34 primary health care clinics. The hospitals are overburdened by the community needs and the high prevalence of HIV/AIDS in the area. The antenatal clinic prevalence of HIV/AIDS in 2007 was 29.1%. The disease burden and other community factors have led to the development of 37 HBC organisations which date back to as early as 1994. These organisations employed a total of 938 CHWs in April 2010. The primary investigator spent 2 ½ years living in Buchbuckridge working as a capacity-builder with a HBC NGO and therefore has intimate knowledge of and strong relationships with the study subject and population.

Recruitment and Enrolment of Study Participants

Community Access

Meetings will be held with all local HBC NGOs to introduce the organisations to the study and to incorporate community feedback. Each of the NGOs with selected CHWs will then be approached and the organisations will facilitate access to the CHWs. The CHWs will then facilitate access to the clients and PCGs.

Inclusion Criteria

Interviewee must be 18 years or older;

Interviewee must be capable of providing informed consent.

Exclusion Criteria

Interviewee who is less than 18 years old;

Interviewees who are too ill or weak to provide informed consent or who lack cognitive ability to do so.

Study Sample Size

Nine home based care organisations (NGOs) have been purposively selected in the parent CHRSA Study to represent the diversity of HBC in BBR. They have been selected to include variety in terms of geographic distribution, access to funding, and age of organisation. Each of the nine organisations will be asked to provide a list of all of their current Community Health Workers

(CHWs). This list will represent the sampling frame for the CHW component of this phase. One or two CHWs will be randomly selected from the sampling frame at each of the NGOs (totalling 15 CHWs). Each of these CHWs will be interviewed according to the interview schedule. Each of the selected CHWs will also be asked to provide a list of all of their current clients. This list will represent the sampling frame for the clients. Two clients for each of the 15 CHWs will be purposively selected by the research team to include a diversity of client illnesses, severity of illness, and patient and patient family socio-demographics (30 clients). Each client will be asked to identify their primary caregiver and this person will also be interviewed (30 PCGs).

In summary, a total of 75 people will be interviewed: 15 CHWs, 30 Clients and 30 PCGs. All of these 75 people will be interviewed on one occasion. 30 of the participants will then have follow-up interviews. These participants will be selected based on their preliminary interview. Participants will be included for a second interview if their preliminary interview left gaps on emerging themes from the rest of the data.

Research Procedures and Data Collection Methods

Interviews for the study will be conducted using a semi-structured questionnaire. A different questionnaire will be used with each member of the triad of care, one for CHWs, one for PCGs, and one for clients. This is to accommodate the different role that each member plays in relation to the provision of care. The interview tools are provided in Appendix A. Interviews will be conducted in the local language of either Xitsonga or Sepedi by three teams of two interviewers, all of whom are fluent in the local languages and in English. All research team members will undergo extensive training on qualitative methods, on home-based care background and on appropriate translations of study questions. They will then conduct practice interviews amongst themselves and with study coordinators to ensure accurate and high-quality interview skills. There will be an initial in-depth interview to collect preliminary data using the structured questionnaire. Each interview is anticipated to take approximately 1 ½ hours. Approximately one month after the initial interview a follow-up interview for clarification and elaboration will be conducted with some interviewees. Interviews will be recorded using a voice-recorder, and field notes will be documented at the end of each interview.

Data Safety and Monitoring

Daily study performance for all components of the CHRSA Study is the responsibility of the study coordinator. The study coordinator will meet weekly with study field worker teams to address any challenges that may arise. This will include ensuring that participants' safety is being maintained by the study. The audio recordings will be destroyed following completion of the transcription to ensure confidentiality. All transcripts will be backed up on flash drives on a daily basis.

Additionally, all completed transcripts will immediately be emailed to the study coordinator and P.I. to ensure that there are protected, updated copies of all transcripts on three separate computers which all have up-to-date antivirus software.

Data Analysis

Audio recordings will be transcribed and translated on a weekly basis by the field workers who conduct the interviews to ensure accuracy of transcription and translation. The field workers have previously been trained on data transcription and translation, but will have a refresher training to ensure accuracy. The transcript will be checked by both members of the field work team to ensure accuracy. The study coordinator and the P.I. will then check the transcripts for comprehension. Data will be analysed throughout data collection to ensure data quality and to assess data for saturation.

Data analysis on the health information content will be conducted by the P.I. of the HIH study throughout the data collection process through immersion and intimate knowledge of data. The same data will be independently coded by two other researchers and codes and themes will be checked to ensure analysis credibility. The HIH study PI will continually be in contact with these other coders to discuss emerging themes and to ensure trustworthy interpretation. Data will also be triangulated between the members of the triad of care to ensure accuracy of information. The data will be systematic and coherently coded into reoccurring ideas, themes, theoretical constructs and theoretical narratives. The data will be analysed with particular reference to the health information needs, services, preferences and trainings amongst this triad of care. Health information needs will be inferred indirectly and directly from interviews. Analysis will seek to ascertain the quality of health information care, as defined as the degree of fit between health promotion needs/ desires and health promotion provision. It will then postulate factors that facilitate or impede the quality of health information services.

The P.I. will continually discuss the interviews with the field workers and with research team colleagues to ensure accuracy of interpretation. Additionally, the P.I. will approach the data reflexively in order to examine the way her experiences with HBC influence her interpretation of the data, yet will ensure that all hypotheses are grounded in what the study participants actually say during interviews. Finally, initial data interpretations will guide the follow-up questions and will be presented to study participants to ensure that the interpretations are appropriate and coherent.

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Ethical Considerations

Description of Risks and Benefits

Potential risks/discomforts

The researchers anticipate that this study will involve minimal physical, social, economic, legal or psychological risks associated with participation. Privacy and confidentiality will be ensured to minimise this risk. Participants will be informed that their participation is entirely voluntary and of their right to refuse to participate or to discontinue their interview at any point during the study without any impact on their future care or employment. If any emotional or psychological harm is noticed or is reported by the participant, the interviewer will request that the participant consult a counsellor in the vicinity of the nearest health facility. The content of the interview may include some sensitive matters, but this risk is expected to be low. It is possible that some participants may experience emotional harm by discussing sensitive information regarding their care experience. It is also possible that should participants be referred to, and utilise health services there could be an added burden upon the health service. All of these considerations will be monitored in order to mitigate risks.

Benefits

There will not be any direct benefit for participating in the study and study participants will not receive any form of reimbursement for their participation as the interviews will not require transportation costs. However, participation in the study will allow participants to share their experiences with the researchers. Additionally, study interviewees will receive an assortment of fruits as a token of appreciation for their time. The results of the study will be used to inform policy, and to generate the quality of care assessment tool which will be used in the quantitative stage of the broader Quality of Care in the Home study and adapted for use by local NGOs and donors. Documentation of rural experiences HBC care will help to ensure that these voices are heard and that policy and programs are appropriate for rural contexts. Given the minimal risks and large potential societal benefits, the harm to benefit ratio is favourable for study participants.

Informed Consent Process

During the voluntary, informed consent process, the interviewees will consent to all parts of the CHRSA Study which include the HIH analysis of health information content. All interviews and informed consent processes will be conducted in the interviewees preferred language. Information on the study will be provided and discussed with potential study participants prior to an interview. No information will be withheld. The information leaflet will be available in English, Xitsonga, and Sepedi. The Xitsonga and Sepedi versions of the consent forms utilise simplified language to ensure participant understanding. The field worker will verbally explain the study information and consent form to study participants. During this process, the field work team will ensure that participants comprehend the study and that their participation is entirely voluntary. The team will be trained on the informed consent process during their training prior to the start of data collection. Participants will be able to discuss their participation with their families, friends or advisors.

The English information leaflet has been attached in Appendix B. Should the participant agree to participate in the study, informed consent for participation and for voice-recording will be obtained prior to the start of the interview. The informed consent forms will be available in English, Xitsonga, and Sepedi. The English informed consent forms have been attached in Appendix C. Participants who are unable to write their names will have the information sheet and consent form verbally explained to them and will be requested to draw an “X” on the forms to indicate their consent. If a patient provides informed consent to be interviewed but declines to be voice-recorded, the field workers will conduct the interview and take extensive notes in replace of the voice-recording.

During the follow-up interviews, study participants will be reminded of the study information and of their prior consent. They will also be reminded that they are free to refuse to participate in the interview. During this time they will also be informed that they can contact the UCT HREC with any concerns. They will receive a handout which states, “Please note: This clinical study protocol has also been submitted to the University of Cape Town, **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 CHRSA Study**, you may contact Prof. M. Blockman, Chairperson of the University of Cape Town Health Sciences Faculty Human Ethics Committee at 021 406 6626.

Privacy/Confidentiality

Interviews will be conducted in the comfort of the client, CHW, or PCG home or any other venue that is deemed appropriate by both the interviewer and interviewee. Efforts will be taken to ensure that interviews with clients, PCGs and CHWs are all conducted separately from one-another in a confidential manner to prevent affecting the relationship amongst the participants. All data will be maintained confidentially by the study coordinator to ensure that interviewee rights are not infringed upon. Participant names will not be recorded in the interviews, but rather each participant will be identified by a code such as 1C for Triad 1 Client or 4P for Triad 4 Primary Caregiver. Participant names will be confidential and participants will not be identified in any report or publication made on the study. Study tapes will be transcribed and then destroyed. All study data including interview transcripts and study journals will be held in a secure location for three years following the completion of the study before being destroyed.

Prior Ethical Approval

Approval to conduct the Care in the Home in Rural South Africa study was received from the Human Research and Ethics Committee at the University of Witwatersand. The Mpumalanga Provincial Ethics committee and the national Department of Social Development committee also provided approval for the study. Ethical approval for the Quality of Care in the Home: Community Health Workers and Health Promotion Study was obtained from the University of Cape Town Human Research and Ethics Committee. This study will be conducted in accordance with the latest Declaration of Helsinki (2008) and with the Department of Health: Ethics in Health Research: Principles Structures and Processes (2004). A copy of the ethical approval forms are included in Appendix F.

Dissemination of Results

Results from the study will be written up and submitted for publication in an academic peer-reviewed journal. The study results will also be disseminated to the community through community representatives involved in the research process including HBC management, departmental representatives and community leaders. All of these stakeholders have been involved in the development and implementation of the study and it is hoped that study findings will inform government and funder policy along with HBC NGO practice.

Research Team

HIH Study Principal Investigator: Rose Zulliger completed her undergraduate degree in Public Health at Johns Hopkins University in the United States of America. Upon graduation in 2007, she moved to South Africa to serve with the United States Peace Corps as a Community HIV/AIDS Outreach Programmer working for a Home-Based Care organisation in the village of Acornhoek within Bushbuckridge, Mpumalanga. She also coordinated research studies in the local ARV clinic for Rural AIDS Development Action Research (RADAR) of the University of Witwatersrand. In 2010 she moved to Cape Town to pursue a Masters in Public Health at the University of Cape Town. Her advisor on her thesis study is Dr. Helen Schneider. Zulliger's interests include health promotion, youth and female health issues, and the role of CHWs, particularly as they relate to HIV prevention and care. She currently works in the Centre for Infectious Disease and Epidemiological Research (CIDER) at UCT and will be starting her PhD in Health, Behaviour and Society at the Johns Hopkins School of Public Health in August 2011.

CHRSA Study Leader/ Primary Investigator: Dr. Mosa Moshabela is currently a PhD student at the University Of Witwatersrand School Of Public Health. Interests include infectious diseases particularly HIV and TB. Co-investigator in a number of research initiatives including an ongoing 5-year cohort study of HIV infected individuals in rural South Africa, a retrospective cohort study aimed at investigating predictors of mortality in HAART patients currently under data collection and a Site Investigator for the Mpumalanga research site of the 4-province study called Researching Equity and Access to Healthcare (REACH). A qualified physician, Dr Moshabela is also a Lecturer at the School of Public Health, University of Witwatersrand and director of the Rural AIDS Development Action Research (RADAR) programme of the University of Witwatersrand.

References

- Bond, V.A., Tihon, V., Muchimba, M., Godfrey-Faussett, P. (2005). 'Kuyendela odwala TB'--visiting TB patients: the widening role of home-based care organisations in the management of tuberculosis patients in Lusaka, Zambia. *Int J Tuberc Lung Dis*, 9(3), 282-7.
- Cullinan, K. (2000). Community-based care. Editorial, *Health Systems Trust*, 58, 1-12.
- Desmond, C., Gow, J., Loening-Voysey, H., Wilson, T., Stirling, B. (2002). Approaches to caring, essential elements for a quality service and cost-effectiveness in South Africa. *Evaluation and Program Planning*, 25(4), Pages 447-45.
- Friedman, I. (2005). Community health workers and community caregivers: towards a model of unified practice. In: Ijumba P, Padarath A, (eds). *South African Health Review 2005*. Durban: Health Systems Trust.
- Gilson. L., Gill. W., Heggenhougen. K., Owuor-Omondi. L., Perera. M., Ross. D., Salazar. L. (1989). National Community Health Worker Programs: How Can They Be Strengthened? *Journal of Public Health Policy*, 10(4), 518-532.
- Harding, R., Karus, D., Easterbrook, P., Raveis, V.H., Higginson, I.J., Marconi, K. (2005). Does palliative care improve outcomes for patients with HIV/AIDS? A systematic review of the evidence. *Sex Transm Infect*, 81(1):5-14.
- Kang'ethe, S.M. (2009). Challenges impacting on the quality of care to persons living with HIV/AIDS and other terminal illnesses with reference to Kanye community home-based care programme. *SAHARA J*, 6(1):24-32.
- Lawn, J.E., Rohde, J., Rifkin, S., Were, M., Paul, V.K., Chopr, M. (2008). Alma-Ata 30 years on: revolutionary, relevant, and time to revitalize. *Lancet*, 372: 917-27.
- Lehmann, U., Sanders, D. (2007). *Community health workers: What do we know about them? The state of the evidence on programmes, activities, costs and impact on health outcomes of using community health workers*. Geneva: World Health Organisation.
- Lehmann, U., Friedman, I., Sanders, D. (2004). *Review of the Utilisation and Effectiveness of Community-Based Health Workers in Africa. A Joint Learning Initiative: Human Resources for Health and Development Working Paper 4-1*.
- Mabude, Z.A., Beksinska, M.E., Ramkissoon, A., Wood, S., Folsom, M. (2008). A national survey of home-based care kits for palliative HIV/AIDS care in South Africa. *AIDS Care*, 20(8):931-7.
- Naidu, V. (2005). *The Evaluation of Costs and Process Indicators for Home Community Based Care (HCBC) Programmes: PHASE 1 REPORT*.
- Ncama, B.P. (2005). Models of Community/ Home-Based Care for People Living with HIV/AIDS in Southern Africa. *Journal of the Association of Nurses in AIDS Care*, 16(3), 33-40.
- Ndaba-Mbata, R.D. & Seloilwe, E.S. (2000). Home-based care of the terminally ill in Botswana: knowledge and perceptions. *International Nursing Review*, 47, 218-223.
- Odindo, M.A., Mwanthi, M,A. (2008). Role of governmental and non-governmental organizations in mitigation of stigma and discrimination among HIV/AIDS persons in Kibera, Kenya. *East Afr J Public Health*, 5(1):1-5
- Olenja, J.M. (1999). Assessing community attitude towards home-based care for people with AIDS (PWAs) in Kenya. *Journal of Community Health*, 24(3), 187-199.
- Omer, P. (2006). Psychosocial impacts on caregivers of people living with AIDS. *AIDS Care*, 18(3), 236-240.

- Qukula, T., Watkins, M. (2009). *Community Based Services: Audit of Current CBS and Funding Streams*. Draft. Report for DEXCO. June 2009.
- DoH. (Department of Health). (2001). *National Guideline on Home-Based Care/ Community-Based Care*. Compiled By the Directorate: Chronic Diseases, Disabilities and Geriatrics.
- DoH. (2004). Speech by Minister of Health, Dr Manto Tshabalala-Msimang, at the launch of the Community Health Worker Programme, 26 February 2004.
- Schneider, H., Hlophe, H., van Rensburg, D. (2008). Community health workers and the response to HIV/AIDS in South Africa: Tensions and prospects. *Health Policy and Planning*, 23(3), 179-187.
- Uys, L.R. (2002). The practice of community caregivers in a home-based HIV/AIDS project in South Africa. *Journal of Clinical Nursing*, 11, 99-108.
- Uys, L.R. (2003). Aspects of the Care of People with HIV/AIDS in South Africa. *Public Health Nursing*, 20(4), 271–280.
- WHO. (2002). *Community/ home-based care in resource-limited settings: A framework for action*. Geneva: World Health Organisation.
- Witmer, A., Seifer, S.D., Finocchio, L., Leslie, J., O’Neil, E.H. (1995). Community health workers: Integral members of the health care work force. *American Journal of Public Health*, 85(8), 1055.

PART B

Community Health Worker Role Reconsideration:

A Review of the Literature

Community members have long served a wide range of roles which have included preventive, promotive, care, rehabilitative, and palliative care along with community mobilisation (Friedman, 2005). Community Health Workers (CHWs) were conceived as holistic, generalist workers who addressed the varied needs of their communities (Gilson et al., 1989). Yet, provision of care by CHWs in communities confronted with a quadruple burden of disease- including a high prevalence of HIV/AIDS- has become synonymous with care for the very ill and dying. Scholarly articles in the African context highlighted the value of community caregivers as providers of nursing and palliative care (Defilippi et al., 2007; Fox et al., 2002; Ncama, 2005). By 2009, the majority of CHWs (57%) in South Africa provided services specifically for those with TB & HIV rather than more generalist care, although there was growing emphasis on more general care (Lehmann et al., 2009).

This trend towards more generalist care is part of a broader revitalisation of the primary health care system and of CHWs. South African CHWs' central mandate, according to new national policy, is to identify health needs, facilitate service access, provide community-based information, education and psychosocial support, deliver basic health care, and support community campaigns. These more preventative and promotive services include the provision of information, education and communication (IEC) within an integrated primary health care team (DoH, 2010). The goal of these preventative and promotive health services include provision of community health education and interventions which can promote health behaviours and reduce disease transmission (Qukula & Watkins, 2009). Thus, there has now been a clear shift in the prioritization of CHWs roles away from palliative and curative care.

This CHW role reconsideration warrants further investigation of the factors which have shaped South African policy. This review of the literature will explore the shift to answer, *what is the context for the evolution of CHWs as purveyors of various forms of Information, Education and Communication in the home and what evidence has influenced this evolution?* The paper will

specifically look at the IEC role that CHWs play in non-governmental, home-based care (HBC) organizations, as described in the literature, in order to inform the Health Information in the Home (HIH): Appropriateness and Quality of Community Health Workers' Health Information Provision in a Rural South African Sub-District study.

The methods of and terminology used in the literature review are presented first, followed by a discussion of the foundation for CHWs around the world and within South Africa to highlight the historical context for the evolution of CHWs. The paper then addresses the literature on historical and contemporary roles of CHWs to explore the CHW role evolution and its causes. The concept of IEC is defined and the potential role for CHWs in IEC is highlighted. Finally, the review presents the current evidence on CHW IEC services which has influenced this shift in the CHW role.

Methods

Community Health Worker Literature

In March 2009 the primary author conducted a systematic literature review on community health workers based on Cochrane Review recommendations to inform the HIH study parent proposal.

Key search terms were:

- “Home-Based Care”
- “Home Based Care”
- “Community Caregiver”
- “Community Health Worker”
- Home-based care guideline
- AIDS Volunteer Care

These terms were searched on PubMed, ESR Nexus, EbscoHost, ScienceDirect, JSTOR, HRH Global Research Center, Google and Google Scholar. Inclusion criteria were studies which focused on home-based care by any of the aforementioned groups of care workers. Studies that did not use non-professional community health worker were excluded. Particular attention was given to theoretical and review articles along with those based on studies from the developing world. The search was supplemented with key referenced documents and with policy documents along with gray literature and personal communication.

In January 2011 the review was updated using the search terms:

- “Home-Based Care”
- “Home based Care”
- “Community Caregiver” HIV
- “Community Caregiver” Africa
- “Community Care Worker”
- “Community Health Worker” .

These terms were searched in PubMed, EbscoHost and JSTOR. Articles were included which were published in a peer-reviewed journal between February 2009 and January 2011. Particular emphasis was placed on theoretical articles or those based on research within Africa. Relevant referenced and updated policy documents were also included along with gray literature from South Africa.

IEC, Health Care Access and Traditional Medicine Literature

Development of the study proposal and subsequent data analysis necessitated the reading of literature beyond that directly related to CHWs. Literature was purposively selected by the primary author and by her advisor to contextualise the study findings within the literature. Additionally, the term, “Information Education Communication” was searched on PubMed and Google Scholar.

All article abstracts were read to determine eligibility and those relevant to CHW work in the African context were included. Summaries of key included articles are attached in Appendix D. This paper presents a narrative synthesis in response to the study questions on CHW role reconsideration to generate a comprehensive overview of the current state of the literature. Where appropriate, limitations of included articles are highlighted.

Home Based Care Terminology

Community Health Workers

There is a variety of terms used in the literature and colloquially when referring to community health workers including “community care workers”, “community caregivers”, “home-based caregivers”, “community based health workers” and “lay health workers”. These terms refer to community members who, ideally, are given a limited amount of training to carry out health and

welfare services within their own communities. These workers should be supported by the health systems, yet held accountable by their own communities (Lehmann & Sanders, 2007; Friedman, 2005; Gilson et al., 1989; Schneider et al., 2008). Within South Africa, CHWs are not formally employed by the government, but rather are stipended by non-governmental organizations who act as intermediaries (Lehmann et al., 2009). The etymology of this role and associated terms will be discussed in the *Historical Context for CHW Role Evolution* section. This paper will utilise the term, community health worker because this is the term currently being used by the South African Department of Health. For the purposes of this paper, CHWs are considered to be non-professional community members who have received some training to provide promotive, preventive, curative, rehabilitative and psychosocial support in the home. CHWs supplement the informal and primary caregiving activities often performed by patients' family and friends.

Community-based health workers provide a wide range of public health functions and home-based care is one specific group within this workforce (Akintola, 2010; Friedman, 2005). The World Health Organization broadly defines Community Health Care (CHC) as “any form of care given to ill people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities. The goal of CHC is to provide hope through high-quality and appropriate care that helps ill people and families to maintain their independence and achieve the best possible quality of life.” (WHO, 2002).

Historical Context for CHW Role Evolution

CHWs around the World

CHWs are not a new phenomenon in the world, but have been providing health services for nearly one hundred years. One of the most notable and influential early uses of CHWs was the “barefoot doctors” program in China (Lawn et al., 2008). Despite this long history, CHWs only came into prominence as a mechanism for providing services in the early 1980s. This emphasis was related to the introduction of Primary Health Care paradigm in the WHO declaration of Alma Ata (Schneider, et al., 2008). The declaration “promoted a comprehensive approach to improving health” (Travis, et al., 2004). CHWs would be central in the advancement of primary health by generating understanding of and appreciation for health services by underserved populations (Abbatt, 2005). CHWs filled a variety of roles, but were generally seen as both health workers and as community advocates serving as catalysts of social change (Lehmann & Sanders, 2007).

Interest in CHW programmes, however, began to wane by the late 1980s as programmatic limitations emerged (Lehmann & Sanders, 2007). These challenges included unrealistic expectations of volunteers, lack of community ownership in the programmes, poor programmatic planning, and problems with sustainability and quality maintenance (Gilson et al., 1989). The economic recession and subsequent World Bank-driven policies of structural adjustment further led to the collapse of most large-scale, national programmes (Lehmann & Sanders, 2007) as did the perception that some vertical health initiatives were more successful (Haines et al., 2007). CHW services did not disappear completely, but continued to operate on the periphery of the health services until the emergence of HIV/AIDS.

The services and roles of CHWs who provide HBC have evolved over the past decades and continue to do so in order to meet local contexts. HBC for people living with HIV/AIDS (PLWHAs) first emerged in North America and Europe in order to provide more comprehensive and cost-effective care (Ncama, 2005). The service has now rapidly spread throughout Africa, including South Africa. HIV/AIDS had a profound effect on health services throughout the world and CHWs were seen as a mechanism for mitigating these systemic effects (DoH, 2001). Additionally, CHWs came back into prominence globally as the World Health Organization (WHO) promoted task-shifting to alleviate over-stretched health care systems (Schneider, et al., 2008). These initial efforts at HBC around the world were ‘unsystematic and needs-based’, necessitating a programmatic and organised approach to care provision. This was provided in 2002 by the WHO framework for the establishment and maintenance of community and home based care (WHO, 2002). It is clear that the role of CHWs around the world has been influenced by policy initiatives, financial realities and health needs. The historical developments of CHWs around the world and specifically within South Africa are shown in the timeline in Table 1. The history, practices, and progression of HBC within South Africa will now be discussed to contextualise South African CHWs within the broader CHW role reconsideration.

Table 1: Key CHW Developments in South Africa and Around the World

Pre-1978	Early 1980s	Late 1980s	1990s	2000s
<p><u>International</u> CHWs informally provide health services in a variety of countries, particularly Asia</p> <p><u>South Africa</u> CHWs are utilised as outreach agents and malaria educators</p>	<p><u>International</u> CHWs come into prominence following introduction of primary health care paradigm at Alma Ata</p> <p><u>South Africa</u> CHWs operate on a small scale in “homelands”</p>	<p><u>International</u> Interest wanes following emergence of limitations and economic and policy shifts HBC for PLWHA emerges</p> <p><u>South Africa</u> CHWs operate on a small scale in “homelands”</p>	<p><u>International</u> CHW use rapidly spreads in response to HIV and health workforce shortages</p> <p><u>South Africa</u> CHWs are identified as key solution to health worker shortage State begins financial support, but are responsibility of provinces</p>	<p><u>International</u> WHO releases framework CHWs used to access hard-to-reach groups and for task-shifting</p> <p><u>South Africa</u> SA DoH releases CHBC guidelines CHWs seen as vital part of PHC team linking formal health sector to the community</p>

CHW History of South Africa

CHW use in South Africa has also waxed and waned, alongside international changes in policy initiatives, financial realities and health needs, but also due to local political developments. CHWs have a rich and extensive history within South Africa which dates back to the 1930s and 40s. Early initiatives included a malaria programme in the area that is now Kwa-Zulu Natal and, notably, with the Pholela rural health unit. Developed in the 1940s by Sidney and Emily Clark, the health unit utilised CHWs at outreach agents in communities. This project served as part of the foundation of the Primary Health Care paradigm. These CHW projects, however, lost support for political reasons as responsibility for rural, black health was shifted to ‘homeland’ departments of health (van Ginneken, et al., 2010).

After this initial decline in CHW use, some CHW programs re-emerged to address the large gaps left by the government services (van Ginneken et al., 2010). HBC programmes in South Africa

were initially started by non-governmental organisations (NGOs), community-based organisations (CBOs), faith-based organisations (FBOs), and concerned individuals (Cullinan, 2000). In the early 1990s there were a series of workshops around the important role of CHWs in the new ANC health plan, but this initiative lost support and the actual plan reduced emphasis on CHWs. In 1996 the national government transferred responsibility for CHWs to provincial governments who, subsequently, have had different commitments to CHW programs (Friedman, 2005).

By the mid to late 1990s, HBC organisations emerged across the country to provide HIV- and orphan-related services (Schneider & Lehmann, 2010). At roughly the same time, the South African government became more supportive of CHW programs and began to financially support NGO employment of CHWs (Schneider et al., 2008). In 2001 the South African government released a national guideline for HBC/ Community Based Care. Home-based care was identified as a solution to the shortage of hospital beds, health professionals, and resources, given the difficulty of hospitalisation of patients with long-term, terminal illnesses (DoH, 2001). The CHW Policy Framework explicitly stated that the preferred model of service delivery is a government-NGO partnership in which the NGOs receive government funds to employ the workers (Schneider et al., 2008). The guidelines proposed that the formal sector would be the overarching body responsible for planning and managing HBC and supporting its work. The informal sector, such as NGOs, would have responsibilities which include operational coordination, direct care, M&E, and referrals (DoH, 2001). In 2000 the South African government allotted specific funding for the expansion of home and community based care and voluntary counselling and testing (Schneider & Lehmann, 2010). The South African health and social sectors jointly worked on developing a revised framework to address the growing body of CHWs, and more recently the Department of Health has released its own discussion document (DoH, 2010).

“Massive training of community-based workers” was identified as a fast step towards achieving the Millennium Development Goals (UN Millennium Project 2005, cited in Abbatt 2005) and the increase in the number of CHWs has been dramatic. In 2004 there were an estimated 40,000 of these lay workers in South Africa (DoH 2004a) which was nearly equal to the number of professional nurses (43,660). By 2008 the CHW cadre had grown to include an estimated 65,000 of these workers who performed a broad range of services which include HBC (Schneider & Barron, 2008; DoH, 2006). This massive growth has led to what has been described as the “poorly

described and characterised, regulated (including training) and managed” current state of the CHW system (Schneider & Barron, 2008, p 10). In light of this evolving notion and policy context of CHWs, this paper will now discuss how the CHW role in has shifted, both internationally and within South Africa.

CHW Role in HBC

International Evolution

The role of CHWs has evolved over the long history of the cadre. Initially, CHWs were expected to serve a range of community services including provision of health care, community advocacy and mobilisation (Lehman & Sanders, 2007). Witmer and colleagues in 1995 explained that the essential concept of community health work is to empower community members to identify their own needs and to implement their own solutions. CHWs effectively served two- at times conflicting- roles as both extensions of the formal health care system and as political agents who mobilised communities (Standing & Chowdhury, 2008). These broad roles were inhibited by the abovementioned unrealistic expectations of CHW and by the collapse of financial support for CHW programmes. Additionally, there is evidence that the communities demanded curative services which CHWs were unable to provide, leading to a perceived lack of credibility and the failure of some programmes (Sanders, 1985).

CHWs re-emerged around the world with an altered role. It was envisioned that CHWs could play central developmental and promotional roles, particularly by bridging between the formal sector and the home (Lehman & Sanders, 2007). Thus, CHWs were re-envisaged as key mediators who could “increase both the effectiveness of curative and preventive services and, perhaps more importantly, community management and ownership of health-related" services rather than act as catalysts social change (Kahssay et al., 1998).

South African Reprioritisation

This same role evolution was experienced in South Africa. The 2001 South African framework proposed a broad definition of HBC which classically defined HBC services as preventative, promotive, therapeutic, rehabilitative, long-term maintenance, and palliative care (DoH, 2001). Thus, CHWs were to provide a broad range of services within the home, but, in practice, “CHWs

are used primarily to render basic, mostly curative health services within homes and communities and to assist health professionals with their tasks” (Lehmann & Sanders, 2007). The emphasis has continued to be on comprehensive services, but the value of promotive services has gained prominence with time. In a 2004 document the former Minister of Health identified health promotion services as a CHW programmatic “imperative” (DoH, 2004). There continue to be debates around the use of CHWs to provide general, holistic services or specialised services, but by 2010 there appeared to be consensus that CHWs play a central role in health promotion (DoH, 2010).

The final draft of Department of Health’s *Re-engineering Primary Health Care in South Africa Discussion Document* envisions CHWs as integral members of a nurse-led team which provides community based services. The purpose of the team is to make health care more pro-active and to keep families healthy through promotive and preventive services. Within the teams, CHWs serve as the vital link between the community and the formal health services. Specifically, CHWs are to provide comprehensive services which pay particular attention to the quadruple burden of disease. The roles and functions of CHWs are described as follows:

- “Screening
- Assessment & referral,
- Information & education,
- Psychosocial support,
- Basic home Rx
- Support community campaigns, schools” (DoH, 2010).

Thus, CHWs’ central function is primarily preventive and promotive (e.g. screening, education, and community campaign services). There is only one reference to basic curative services and no direct reference to palliative services. This represents a large shift from early documentation of CHW roles in which these services were central. Given the clear emphasis on CHW provision of different forms of IEC services in the home, it is important to understand the concept of IEC.

Information, Education and Communication (IEC)

IEC is a group of initiatives which seek to influence individual behaviour and community norms. This is done through a variety of mediums to empower people to initiate or maintain healthy behaviour and to develop social norms which facilitate such behaviour. The roots of IEC, much

like those of CHWs, are within a primary health care paradigm, particularly in its emphasis of a client-centred, accessible approach (WHO, 2001). Since its conception, there have been a number of lessons learned regarding the effectiveness of IEC, some of which are relevant to its implementation by CHWs. A 2001 WHO paper assessing the use of IEC within reproductive health programming found the following general lessons:

- “The most important lesson learned in **IEC** is that it **works**. It creates awareness, increases knowledge, changes attitudes and moves people to change or continue their behaviour or to adopt an innovation.
- Very rarely does a person make a decision alone. To make a lasting change in one individual, the **key influentials** must be identified and encouraged to support these changes.
- Mass media helps to create an agenda for public debate. It reaches many people and is not that expensive. However, to be effective, **mass media must be supported by interpersonal and group communication**.
- Communication channels should ensure availability of **feedback** mechanisms. This is important for reinforcement and for clarifying questions and issues.” (WHO, 2001, p 3)

These lessons are particularly relevant because they highlight the potential that CHWs have to ensure effective IEC.

CHWs' Promotional and Preventative Potential

In addition to their role facilitating various IEC services within the home, CHWs have the capacity to help patients to apply IEC lessons and access formal health services. A conceptual article by Nemcek and Sabatier highlighted the capacity of CHWs to “serve as a bridge between peers and health professionals” (p 261) and to “establish vital links between health providers and the community” (p 262). They identified three goals of large-scale, culturally-competent CHW use:

1. *Therapeutic alliance*- facilitation of links between the community and the formal health services and strengthening of patient-provider relationship
2. *Improvement of health care utilization*
3. *Reduction of community health risks through education* (Nemcek & Sabatier, 2003)

Provision of IEC services is clearly now part of the CHW mandate within South Africa due to their capacity to serve the aforementioned services. Thus, policies, economics, health conditions and

political realities have influenced the role of CHWs over time and affected what has been seen as CHWs

State of the evidence

CHW Contributions

In light of this understanding of the context of the CHW role reconsideration, it is important to consider what scholarly evidence has informed this evolution. CHWs have been used extensively in the developed world to provide IEC services to high-risk or hard-to-reach populations (e.g. Viswanathan et al., 2009). In this role, CHWs have been found to be effective in communication and in improvement of the local health environment (Abbatt, 2005). One study by Boutin-Foster demonstrated that CHWs could effectively be trained the signs and symptoms of cardiovascular disease which they could then teach to African Americans (Boutin-Foster et al., 2008).

Additionally, a Cochrane systematic review of randomised controlled trials of lay health worker interventions conducted by Lewin et al found, among other things, that lay health workers probably increase breastfeeding and immunization uptake, and “may increase the number of parents who seek care for their sick child” (Lewin et al., 2010, p 3). This thorough summary provides some indication of CHW IEC capacity, but by including only intervention studies it provides little information on the actual, standard CHW services and capabilities. Additionally, most of the included studies occurred in the developing world (55/82) and the generalisability of this evidence to the African context is unclear. It is, therefore, important to discuss the contributions and limitations of literature from the African context.

CHWs have been proposed as key to preventive and promotive service provision, but there is not substantial evidence of how they provide these services within the African context. The scarce articles which exist generally list promotive health services in the form of health education/ promotion/ disease prevention as one of many services provided by CHWs, based on an assumption of adequate provision. The African studies also have substantial limitations. One study on the role played by CHWs in providing TB services within a Zambian community found that HBC was the second-most cited source of TB information by patients. This study interviewed CHWs and patients who did and did not access CHW services in 1999, but focused only on TB patients and failed to explore the impact of these services on patients’ primary caregivers (PCGs)

(Bond et al., 2005). A study from South Africa also found that community caregivers were central IEC providers with 94% of community caregivers indicating that counselling/ informing was a service, compared to only 13% who provided wound care. Care recipients perceived these services as useful, but caregivers work was inhibited by a lack of respect by the formal health care system (Uys, 2002). This study employed rigorous methods and demonstrated that IEC roles are central services within some South African programmes, but it does not explore what counselling / informing services entail or what community IEC needs exist.

A number of studies have specifically explored the role that CHWs can play in reducing community stigma towards people living with HIV/AIDS. A study in Thailand found that an intervention with trained community health volunteers led to a statistically significant reduction in HIV-related stigma (Mashimo, et al., 2001). While this is indicative of the potential of CHWs, the study findings are based on an intervention rather than on the de facto CHW services. Within Africa, Kipp and colleagues found that 16 CHWs in Uganda reported that while stigma was still very strong, PCGs said positive changes had occurred and discrimination against the patients and their families had been reduced, although the role of CHWs in this change is unclear (Kipp, 2007). This reduction was also found by Ncama in her summary of HBC models in southern Africa (Ncama, 2005). A multi-site study which included South Africa stated that frequent discussion-like that facilitated by CHWs- “broke the silence” and was associated with positive indicators such as increased testing for HIV (Hendriksen et al., 2009). Ncama also found that HBC services led to an increase in ease of HIV-status disclosure, and an increase in personal acceptance of HIV status (Ncama, 2007). Thus, there is substantial evidence that CHWs have the potential to reduce stigma through their services in the community.

These studies do not directly give evidence to how stigma is mitigated and are predominantly based on articles with low levels of evidence. Additionally, there is evidence that CHWs themselves become stigmatised which could diminish their ability to effectively provide services in a community. Caregivers are occasionally turned away from patient homes out of fear of being stigmatized (Mills, 2006; Akintola, 2008) and widespread stigma exists towards both HBC clients and the CHWs themselves (McCarragher et al., 2008; Shaibu, 2006; Lindsey, et al., 2003). It is clear that there is insufficient evidence in the literature on CHWs’ non-curative roles with which to inform the role reconsideration.

CHW Challenges

Despite the potential IEC contributions of CHWs, there are a number of negative experiences- beyond stigmatisation of care recipients- highlighted in the literature on their services, including poor training both of CHWs and of PCGs. Common findings indicate that HBC care services are inhibited by low CHW skill and capacity (Ndaba-Mbata & Seloilwe, 2000; Orner, 2006; Uys, 2002; Harding et al., 2005). This low level of CHW capacity may be linked to deficiencies in CHW training which varies substantially in duration and quality and is often not standardized at a national level (Desmond, 2002; Mabude, 2008). A study in Kenya found that there were policies and strategies for the training of PCGs by CHWs, but no strategies for monitoring the implementation of the trainings (Odindo, 2008). Additionally, despite the education provided by HBC organizations, studies in Kenya and Botswana have found that education for PCGs and training in AIDS care remains insufficient (Kange'ethe, 2009; Olenja, 1999) and patients in South Africa were found in a neglected state when admitted into care, highlighting the need for an outreach program to enhance the quality of familial care (Uys, 2003).

In addition to challenges related to CHW training, CHW IEC services are also inhibited by weak relationships with the formal health sector. Organizations are unable to overcome the lack of respect and immense barriers presented by the formal health care system (Uys, 2002) and have poor relationships with the formal health sector (Lehmann et al., 2009). Health centres generally are not interested in HBC services, and despite governmental guidelines' emphasis on continuity of care, there is frequently no formal policy on the partnership between HBC and formal health care or mechanisms for patient-transfer, discharge-planning and referrals (Bond et al., 2005; Mabude, 2008; Shaibu, 2006; Wandwalo, et al., 2004; Mohammad & Gikonyo, 2005; Ogden et al., 2006). This failure results in patients being discharged to families that are not adequately prepared and educated to provide effective care (Zimba & McInerney, 2001). Throughout the literature, the linkages to HBC organizations that would facilitate patient continuum of care remain elusive. It has been hypothesised that the aforementioned insufficient standardization of selection and training inhibited CHW mainstream acceptance (O'Brien et al., 2009).

The poor CHW-clinic relationship is particularly problematic given that there is extensive evidence from South Africa that patients need mediators who are able to bridge the worldviews of

the community and the formal health system. Patients often are unable to effectively communicate with their service providers due to linguistic barriers (Deumert, 2010; Crawford; 1999) or power differentials (Heisler et al., 2009). One study conducted in the same South African sub-district as the HIIH study found that patients were not empowered to clarify instructions from the formal health sector and at times returned home with no clear instructions on how and where to receive care (Goudge et al., 2009). A US study found that CHWs were able to fight these barriers and that they empowered patients with information which helped them to be more assertive in their interactions with health care providers (Heisler et al., 2009). CHWs, therefore, have potential to facilitate therapeutic alliance, yet this service is inhibited by poor relationships with the formal health sector.

Conclusion

In an article on communication of information to disadvantaged populations with the United States, Beacom and Newman aptly stated,

the evidence is mixed for an association between community health worker programs and increases in health knowledge. More rigorous evaluation research is needed to determine if community healthworker interventions represent an effective strategy to reduce health information disparities among disadvantaged groups and to identify the most effective community health worker training and program designs. (Beacom & Newman, 2010)

CHWs have are well-placed to capacitate communities and patient families, reduce persistent stigma with information, and mediate between patients and formal health services- and the need for these IEC services clearly exist. Yet there is insufficient evidence on these services within Africa. It is, therefore, hypothesised that the *role reprioritisation in South Africa is based on policy initiatives, political and fiscal realities, immense need and theorisations of CHW potential, rather than scholarly evidence*. Community demand, coupled with the inability of the South African formal health system to cope with the quadruple burden of needs has led to a strong emphasis on the use of CHWs to reduce the burden on the health sector. The shift from palliative services to promotive services is also indicative of the changing HIV context in the age of public sector access to Highly Active Anti-Retroviral Therapy.

Despite the conceptual support for CHWs as purveyors of IEC services, there remains insufficient evidence upon which to appropriately inform policy and practice. There is a clear need to explore

the current IEC-related needs which exist along with CHW capacities and service provision. It is only when we truly understand the current de facto CHW situation in South Africa that we will be able to develop training and programs which adequately support these services and redress CHW deficiencies of the past. As the cornerstone of a revitalisation in primary health care services, CHWs truly hold the future of South African health in their hands. Evidence is needed to inform and reprioritise their work.

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Literature Review Works Cited

- Abbatt, F. (2005). Scaling up health and education workers: community health workers. Literature review. London: Department for International Development, Health Systems Resource Centre.
- Akintola, O. (2008). Defying all odds: coping with the challenges of volunteer caregiving for patients with AIDS in South Africa. *Journal of Advanced Nursing*, 63(4), 357–365.
- Akintola, O. (2010). What motivates people to volunteer? The case of volunteer AIDS caregivers in faith-based organizations in KwaZulu-Natal, South Africa. *Health Policy and Planning*, 26, 53-62.
- Beacom, A.M., Newman, S.J. (2010). Communicating Health Information to Disadvantaged Populations. *Fam Community Health*, 33(2), 152-162.
- Bond, V.A., Tihon, V., Muchimba, M., Godfrey-Faussett, P. (2005). 'Kuyendela odwala TB'--visiting TB patients: the widening role of home-based care organisations in the management of tuberculosis patients in Lusaka, Zambia. *Int J Tuberc Lung Dis*, 9(3): 282-7.
- Boutin-Foster, C., George, K.S., Samuel, T., Fraser-White, M., Brown, H. (2008). Training community health workers to be advocates for health promotion: efforts taken by a community-based organization to reduce health disparities in cardiovascular disease. *J Community Health*, 33(2), 61-8.
- Cullinan, K. (2000). Community-based care. Editorial. *Health Systems Trust*, 58, 1-12.
- Crawford, A. (1999). “We can’t all understand the whites’ language”: an analysis of monolingual health services in a multilingual society. *Int’l. J. Soc. Lang.*, 136, 27-45.
- Cruse, D. (1997). Community health workers in South Africa: Information for provincial policy makers. Durban: Health Systems Trust.
- Defilippi, K.M., Cameron, S. (2007). Promoting the Integration of Quality Palliative Care- The South African Mentorship Program. *Journal of Pain and Symptom Management*, (33)5, 552-7.
- Deumert, A. (2010). ‘It would be nice if they could give us more language’-- Serving South Africa’s multilingual patient base. *Social Science & Medicine*, 71: 53-61.
- DoH. (Department of Health). (2001). *National Guideline on Home-Based Care/ Community-Based Care*. Compiled By the Directorate: Chronic Diseases, Disabilities and Geriatrics.
- DoH. (Department of Health). (2004). Speech by Minister of Health, Dr Manto Tshabalala-Msimang, at the launch of the Community Health Worker Programme, 26 February 2004.
- DoH. (Department of Health). (2006). Social sector cluster media briefing. 2006, July 7. Pretoria: Author.
- DoH. (Department of Health). (2010). Re-engineering Primary Health Care in South Africa. Discussion Document.
- Desmond, C., Gow, J., Loening-Voysey, H., Wilson, T., Stirling, B. (2002). Approaches to caring, essential elements for a quality service and cost-effectiveness in South Africa. *Evaluation and Program Planning*, 25(4), 447-45.
- Fox, S., Fawcett, C., Kelly, K., & Ntlabati, P. (2002). *Integrated Community-based Home Care in South Africa: A review of the model implemented by the Hospice Association of South Africa*.
- Friedman, I. (2005). Community health workers and community caregivers: towards a model of unified practice. In: Ijumba P, Padarath A, (eds). South African Health Review 2005. Durban: Health Systems Trust.

- Gilson, L., Gill, W., Heggenhougen, K., Owuor-Omondi, L., Perera, M., Ross, D., Salazar, L. (1989). National Community Health Worker Programs: How Can They Be Strengthened?. *Journal of Public Health Policy*, 10(4), 518-532.
- Goudge, J., Gilson, L., Russell, S., Gumede, T., Mills, A. (2009). Affordability, availability and acceptability barriers to health care for the chronically ill: Longitudinal case studies from South Africa. *BMC Health Services Research*, 9, 75.
- Harding, R., Karus, D., Easterbrook, P., Raveis, V.H., Higginson, I.J., Marconi, K. (2005). Does palliative care improve outcomes for patients with HIV/AIDS? A systematic review of the evidence. *Sex Transm Infect*, 81(1):5-14.
- Haines, A., Sanders, D., Lehmann, U., Rowe, A.K., Lawn, J.E., Jan, S., et al. (2007). Achieving child survival goals: potential contribution of community health workers. *Lancet*, 369(9579), 2121–31.
- Hendriksen, E.S., Hlubinka, D., Chariyalertsak, S., Chingono, A., Gray, G., Mbwambo, J., Richter, L., Kulich, M., Coates, T.J. (2009). Keep Talking About It: HIV/AIDS-Related Communication and Prior HIV Testing in Tanzania, Zimbabwe, South Africa, and Thailand. *AIDS Behav*, 13, 1213–1221.
- Heisler, M., Spencer, M., Forman, J., Robinson, C., Shultz, C., Palmisano, G., Graddy-Dansby, G., Kieffer, E. (2009). Participants' Assessments of the Effects of a Community Health Worker Intervention on Their Diabetes Self-Management and Interactions with Healthcare Providers. *Am J Prev Med*, 37(6S1), S270–S279.
- Kang'ethe, S.M. (2009). Challenges impacting on the quality of care to persons living with HIV/AIDS and other terminal illnesses with reference to Kanye community home-based care programme. *SAHARA J*, 6(1), 24-32.
- Kahssay, H., Taylor, M., Berman, P. (1998). *Community health workers: the way forward*. Geneva: World Health Organization.
- Kipp, W., Bajenja, E., Karamagi, E., Tindyebwa, D. (2007). AIDS-related stigma: perceptions of family caregivers and health volunteers in western Uganda. *World Health Popul*, 9(2), 5-13.
- Lawn, J.E., Rohde, J., Rifkin, S., Were, M., Paul, V.K., Chopr, M. (2008). Alma-Ata 30 years on: revolutionary, relevant, and time to revitalize. *Lancet*, 372, 917–27.
- Lehmann, U., Matwa, P., Schneider, S., Colvin, C. (2009). *A Map of Community Care Giver Programme Practices in Provincial Health Departments Report to the Health Systems Sub-Committee of the South National Aids Council (SANAC)*. May 2009.
- Lehmann, U., Sanders D. (2007). *Community health workers: What do we know about them? The state of the evidence on programmes, activities, costs and impact on health outcomes of using community health workers*. Geneva: World Health Organisation.
- Lehmann, U., Friedman, I., Sanders, D. (2004). Review of the Utilisation and Effectiveness of Community-Based Health Workers in Africa. A Joint Learning Initiative: Human Resources for Health and Development Working Paper 4-1.
- Lewin, S., Munabi-Babigumira, S., Glenton, C., Daniels, K., Bosch-Capblanch, X., van Wyk, B.E., Odgaard-Jensen, J., Johansen, M., Aja, G.N., Zwarenstein, M., Scheel, I.B. (2010). Lay health workers in primary and community health care for maternal and child health and the management of infectious diseases. *Cochrane Database of Systematic Reviews* 2010, 3, CD004015. DOI:10.1002/14651858.CD004015.pub3.
- Lindsey, E., Hirschfeld, M., Tlou, S. (2003) Home-based care in Botswana: experiences of older women and young girls. *Health Care for Women International*, 24(6), 486–501.

- Mabude, Z.A., Beksinska, M.E., Ramkissoon, A., Wood, S., Folsom, M. (2008). A national survey of home-based care kits for palliative HIV/AIDS care in South Africa. *AIDS Care*, 20(8), 931-7.
- Mashimo, A., Miura, H., Sakano, S. *et al.* (2001). The role of AIDS volunteers in developing community-based care for people with AIDS in Thailand. *Asian Pacific Journal of Public Health*, 13(1), 3-8.
- McCarragher, D., Cuthbertson, C., Kung'u, D., Otterness, C., Johnson, L., Magiri, G. (2008). Sexual behavior, fertility desires and unmet need for family planning among home-based care clients and caregivers in Kenya. *AIDS Care*, 20(9), 1057-65.
- Mills, E.A. (2006). From the physical self to the social body: expressions and effects of HIV-related stigma in South Africa. *Journal of Community & Applied Social Psychology*, 16(6), 498-503.
- Mohammad, N. & Gikonyo, J. (2005). Operational Challenges Community Home Based Care (CHBC) for PLWHA in Multi-Country Aids Programs (MAP) in Africa Africa Region Working Paper Series No. 88 August 2005 Available at <http://www.worldbank.org/afr/wps/wp88.pdf>
- Ncama, B.P. (2005). Models of Community/ Home-Based Care for People Living with HIV/AIDS in Southern Africa. *Journal of the Association of Nurses in AIDS Care*, 16(3), 33-40.
- Ncama, B.P. (2007). Acceptance and disclosure of HIV status through an integrated community/ home-based care program in South Africa. *International Nursing Review*, 54, 391-397.
- Ndaba-Mbata, R.D., Seloilwe, E.S. (2000). Home-based care of the terminally ill in Botswana: knowledge and perceptions. *International Nursing Review*, 47, 218-223.
- Nemcek, M.A., Sabatier, R. (2003). State of Evaluation: Community Health Workers. *Public Health Nursing*, 20(4), 260-270.
- Odindo, M.A., Mwanthi, M.A. (2008). Role of governmental and non-governmental organizations in mitigation of stigma and discrimination among HIV/AIDS persons in Kibera, Kenya. *East Afr J Public Health*, 5(1), 1-5.
- O'Brien, M.J., Squires, A.P., Bixby, R.A., Larson, S.C. (2009). Role Development of Community Health Workers: An Examination of Selection and Training Processes in the Intervention Literature. *Am J Prev Med*, 37(6S1), S262-9.
- Ogden, J., Esim, S. and Grown, C. (2006). Expanding the care continuum for HIV/AIDS: Bringing carers into focus. *Health Policy and Planning*, 21(5), 333-342.
- Olenja, J.M. (1999). Assessing community attitude towards home-based care for people with AIDS (PWAs) in Kenya. *Journal of Community Health*, 24(3), 187-199.
- Orner, P. (2006). Psychosocial impacts on caregivers of people living with AIDS. *AIDS Care*, 18(3), 236-240.
- Qukula, T. & Watkins, M. (2009). Community Based Services: Audit of Current CBS and Funding Streams. Draft. Report for DEXCO. June 2009.
- Sanders, D. (1985). *The struggle for health. Medicine and the politics of underdevelopment*. London: MacMillan.
- Schneider, H., Lehmann, U. (2010). Lay health workers and HIV programmes: implications for health systems. *AIDS Care*, 22(1), 60-67.
- Schneider, H. & Barron, P. (2008) Achieving the Millennium Development Goals in South Africa through the Revitalisation of Primary Health Care and a Strengthened District Health System. Draft.

- Schneider, H., Hlophe, H., van Rensburg, D. (2008). Community health workers and the response to HIV/AIDS in South Africa: Tensions and prospects. *Health Policy and Planning*, 23(3), 179-187.
- Shaibu, S. (2006). Community home-based care in a rural village: challenges and strategies. *J Transcult Nurs*, 17(1), 89-94.
- Standing, H., & Chowdhury, A.M.R. (2008). Producing effective knowledge agents in a pluralistic environment: What future for community health workers? *Social Science & Medicine*, 66: 2096-2107.
- Travis, P., Bennett, S., Haines, A., Pang, T., Bhutta, Z., Hyder, A.A., Pielemeier, N.R., Mills, A., Evans, T. (2004). Overcoming health-systems constraints to achieve the Millennium Development Goals. *Lancet*, 364, 900-6.
- UN Millennium Project. (2005). *Investing in Development: A Practical Plan to Achieve the Millennium Development Goals*. New York: United Nations.
- Uys, L.R. (2002). The practice of community caregivers in a home-based HIV/AIDS project in South Africa. *Journal of Clinical Nursing*, 11, 99-108.
- Uys, L.R. (2003). Aspects of the Care of People with HIV/AIDS in South Africa. *Public Health Nursing*, 20(4), 271-280.
- van Ginneken, N., Lewin, S., Berridge, V. (2010). The emergence of community health worker programmes in the late apartheid era in South Africa: An historical analysis. *Social Science & Medicine*, 71(6-3), 1110-1118.
- Viswanathan, M., Kraschnewski, J., Nishikawa, B., Morgan, L.C., Thieda, P., Honeycutt, A., Lohr, K.N., Jonas, D. (2009). *Outcomes of Community Health Worker Interventions. Evidence Report/Technology Assessment No. 181*. AHRQ Publication No. 09-E014. Rockville, MD: Agency for Healthcare Research and Quality.
- Wandwalo, E., Kapalata, N., Tarimo, E., Corrigan, C.B., Morkve, O. (2004). Collaboration between the national tuberculosis programme and a non governmental organisation in TB/HIV care at a district level: experience from Tanzania. *Afr Health Sci*, Aug;4(2), 109-14.
- WHO (World Health Organization). (2002). *Community/ home-based care in resource-limited settings: A framework for action*. Geneva: World Health Organisation.
- WHO (World Health Organization). (2001). Department of Reproductive Health and Research. *Information, Education and Communication: Lessons from the Past; Perspectives for the Future*. By Elayne Clift. Occasional Paper 6. Web. 4 Jan. 2011.
<http://www.who.int/entity/reproductivehealth/publications/health_systems/WHO_RHR_01_22/en/index.html>.
- Witmer, A., Seifer, S.D., Finocchio, L., Leslie, J., O'Neil, E.H. (1995). Community health workers: Integral members of the health care work force. *American Journal of Public Health*, 85(8), 1055.
- Zimba, E.W., McInerney, P.A. (2001). The knowledge and practices of primary care givers regarding home-based care of HIV/AIDS children in Blantyre (Malawi). *Curationis*, 24(3), 83-91.

PART C: JOURNAL MANUSCRIPT

Targeted Publication: *Social Science and Medicine*

Abstract

Background: Community Health Workers (CHWs) provide a variety of preventative, promotive, curative, palliative and mediation services. Despite extensive literature on the history and services of CHWs, there is little evidence from Africa on whether they specifically meet the Information, Education and Communication (IEC) needs of their communities.

Methods: This study utilized qualitative methods to explore IEC provision by CHWs within one rural South African sub-district. Semi-structured interviews were conducted in 2010 with CHWs (n=17), their clients (n=33) and the primary caregivers (PCGs) (n=30) who provide care for them, allowing for data source triangulation. 22 follow-up interviews were conducted to further probe the content of and need for IEC in the home.

Results: There is abundant evidence that CHWs provide a range of IEC services in the home. CHWs draw upon their training and experience to provide locally coherent messages for the clients, PCGs and broader community. IEC messages include both illness-specific information and general health promotion. This information enhances PCG caregiving and client self-care capacity. CHWs also assist community members to understand and appropriately utilise government services rather than traditional medicine. Additionally, CHWs mediate between PCGs and clients through information and counselling to reduce stigma and facilitate intra-household communication.

Discussion: As bridges between the two worlds, CHWs re-interpret health information and the conception of illness to make it comprehensible to care recipients. This mediation role enhances CHWs IEC effectiveness and facilitates therapeutic alliance, community risk reduction, and access and adherence to formal services.

Conclusions: CHW play a key role in cultural access to health care and health maintenance, but this function could be compromised by a lack of appropriate trainings and, ironically, by the increasing formalisation of other CHW roles. It is imperative that care is taken to support the CHWs' pivotal role as the interface of informal and formal healthcare.

“She is my teacher and if it was not for her I would be dead”: Exploration of rural South African Community Health Workers’ informational and mediating roles in the home

Introduction

The role of Community Health Workers (CHWs) in South Africa’s health system is being re-prioritised and formalised as part of the revitalisation of primary health care services. CHWs will identify health needs, facilitate service access, provide community-based information, education and psychosocial support, deliver basic health care, and support community campaigns (DoH, 2010). Despite the renewed interest in CHWs’ roles beyond basic health care, there is limited evidence on how these roles have been implemented in the context of “home based care” in Africa.

Recent scholarly articles on the work of CHWs in sub-Saharan Africa have predominantly discussed their nursing and palliative care roles (Ncama, 2005; Demmer, 2007) while informational and mediating roles surrounding the more direct basic health care have received less attention. Existent evidence has indicated that these informational services are flawed and warrant strengthening. Authors have noted that HBC care services are inhibited by low CHW skill and capacity (Ndaba-Mbata & Seloilwe, 2000; Orner, 2006; Uys, 2002) which may be linked to deficiencies and little standardization in CHW training (Desmond et al., 2002). A systematic review by Viswanathan and colleagues (2009) found that there was limited evidence that CHW interventions improve participant knowledge, mixed evidence regarding CHW effectiveness in facilitating behaviour change, and low or moderate strength evidence that CHWs enhance appropriate health care utilization. In light of the clear shift in the CHW mandate towards preventive and promotive work, it is imperative to comprehensively examine CHWs’ current work.

This study explores CHW preventive and promotive services through the perspectives of the CHWs, clients and PCGs involved in care in the home in one rural, South African sub-district. By exploring this work through “multiple perspectives” (Schneider & Lehmann, 2010) the study provides nuanced and rigorous evidence on the de facto provision of care in the home. Informational and mediating needs of clients and PCGs, CHWs’ ability to meet these needs and perceptions of service quality are explored with the objectives to:

1. Assess the self-identified health information needs of PCGs and clients;
2. Assess the nature and extent of information provided by CHWs in homes;
3. Evaluate the degree of fit between CHW health information services and community health information needs;
4. Evaluate the training, communication competencies and sources of health information of CHWs along with their perceived self-efficacy.

Specifically, this article explores the need for and quality of CHWs' Information, Education and Communication (IEC) services (WHO, 2001).

Key Terminology

CHWs have an extensive history within Africa and around the world. These workers have been given a limited amount of training to carry out health and welfare services within their own communities. Ideally, these workers are supported by formal health systems, yet held accountable by communities (Lehmann & Sanders, 2007; Friedman, 2005). Home-based care (HBC) is one cadre within the broader field of community-based health work which is provided by CHWs. This paper will use CHW in reference to HBC caregivers who are affiliated with non-governmental organisations (NGOs).

One specific form of CHW care is the provision of IEC services. IEC represents a group of activities seeking to influence individual behaviour and community norms through a variety of mediums. The ultimate goal of IEC is to empower people to initiate or maintain healthy behaviour and to develop social norms which facilitate such behaviour. The roots of IEC, much like those of CHWs, are within a primary health care paradigm (WHO, 2001). Investigation of contemporary CHW roles must be contextualised within this longer history.

Historical and Contemporary Roles of CHWs

The use of lay health workers in South Africa dates back to their use in the Pholela rural health unit in the 1940s (van Ginneken et al., 2010). Although CHWs have been employed for nearly 70 years, CHWs only came into prominence as a mechanism for providing services in the early 1980s following the 1978 WHO declaration of Alma Ata (Schneider, et al., 2008). CHWs were intended to provide a range of community services including health care, advocacy for their communities and mobilisation of the community as "agents of social change". This broad role was inhibited by

unrealistic expectations of CHWs and collapse of financial support for CHW programmes (Lehmann & Sanders, 2007; Lewin et al., 2010).

CHW services did not disappear completely, but continued to operate on the periphery of the health services until the emergence of HIV/AIDS. CHWs re-emerged because they were perceived as able to bridge between the formal sector and the home (Lehman & Sanders, 2007) and to mitigate the effect of HIV/AIDS on the overstretched health system (DoH, 2001). In 2010 the Department of Health released the *Re-engineering Primary Health Care in South Africa Discussion Document* which envisions CHWs as integral members of a nurse-led team which provides community based services. Within the teams, CHWs serve as the vital link between the community and the formal health services (DoH, 2010). CHWs' central function is primarily preventative and promotive (e.g. screening, education, and community campaign services) rather than purely curative.

Despite the policy emphasis on CHWs' non-curative services, there is insufficient evidence on their actual provision within the African context. Extensive evidence from the developed world does, however, exist which evaluated the use of CHWs. A Cochrane review by Lewin and colleagues included 82 randomised control trials and found moderate evidence that lay health workers enhance breastfeeding and immunization uptake. Other articles explore the potential utility of CHWs in the provision of IEC and mediation of clinic access for hard-to-reach and marginalised populations in the developing world (e.g. Boutin-Foster et al., 2008). Nemcek and Sabatier (2003) theorised that CHWs could “serve as a bridge between peers and health professionals” (p 261) and to “establish vital links between health providers and the community” (p 262). They identified three goals of CHW use:

1. *Reduction of community health risks through education*
2. *Improvement of health care utilization by the community*
3. *Therapeutic alliance-* facilitation of links between the community and the formal health services and strengthening of patient-provider relationship (Nemcek & Sabatier, 2003)

The conception of CHWs as mediators who establish links and who broker community access to government services was also discussed by Schneider & Lehmann (2010).

Thiede (2005) provides a useful framework on health care access. He discusses the critical need to bridge disparate lifeworlds- common assumptions and shared experiences and understanding of the world- between the home and the community in order to facilitate health care access. This is because “[t]he character of disease is best understood by an individual if communicated within the appropriate cultural context of her lifeworld. The same is true for the recognition of need for treatment... Health systems and the community form overlapping lifeworlds... the greater the overlap between the two lifeworlds, the more preconditions for universal access are fulfilled” (Thiede, 2005, pp 1456, 1459). Despite CHW theoretical potential to transcend the lifeworlds of the clinic and home, there is little evidence as to whether this currently occurs, specifically within the African context beyond intervention studies. This study explored the provision of these services by CHWs in a rural, South African context to investigate CHWs capacities and areas for future development.

Study setting

The study was conducted in the rural sub-district of Bushbuckridge, South Africa. Bushbuckridge is a 2,123 square kilometre area comprised of two former Apartheid-era “homelands” that is inhabited by approximately 620,000 people. Bushbuckridge persists today as an almost entirely black African area which is characterised by economic under-development and poverty (>85% of adults are not engaged in formal employment) (Business Trust & DPLG, 2007). Thus, the sub-district has been designated as one of the 22 poorest areas of South Africa (DPLG, 2007) and an assessment of the 22 nodes found that Bushbuckridge had the worst service delivery of all nodes (DSD, 2006). The 30 clinics and 3 hospitals in the area confront a populace facing a quadruple burden of poverty, infectious disease, non-infectious disease and violence/injury. HIV has been particularly virulent within this context of poverty and the antenatal clinic HIV prevalence was 29.1% in 2007 (Lurie et al., 2008). A large body of NGOs have developed in Bushbuckridge in response to this range of health and social service needs, the majority of which are HBC organisations (37 out of the 47 identified) and all of whom utilise CHWs. Bushbuckridge was selected due to the diversity and breadth of HBC organisations. Additionally, the primary author had extensive experience working with the local organisations which facilitated community access.

Methods

This study explored the need for and provision of IEC services in the home by CHWs working in nine HBC organisations. 80 semi-structured interviews were conducted with 33 clients, 30 PCGs and 17 CHWs totalling 33 triads. A triad is defined as the trio of a client, his/her PCG and CHW. Interviews were conducted with the entire triad of care in order to ensure reliability of findings through triangulation of sources. This technique is novel in CHW literature and represents a key method for future studies to ensure clear understanding of care in the home.

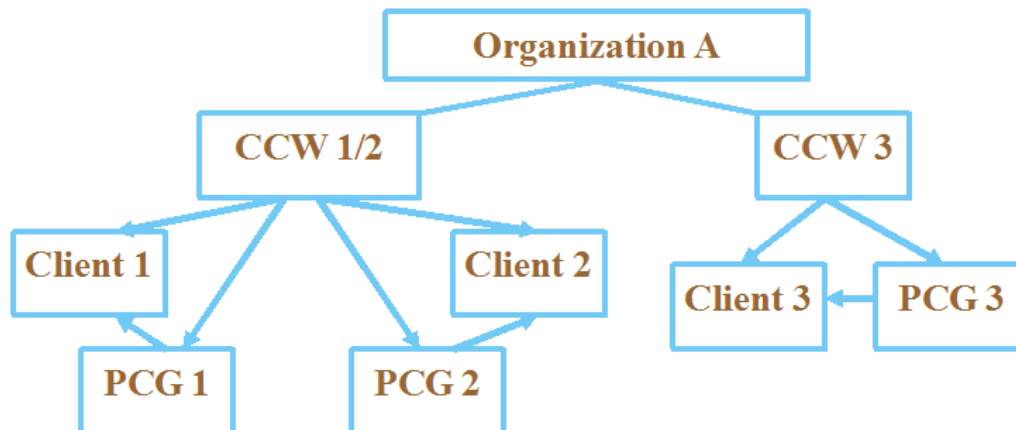
The sampling method is summarised below in **Table 1**. Preliminary, semi-structured interviews were conducted in BBR in 2010 by teams of local field workers. Translated questionnaires tailored towards their care role were used with the CHWs, clients and PCGs. The questions explored illness experience, triad roles and relationships along with perceptions of the quality of care provided. All interviews were conducted in the languages of sePedi, xiTsonga and isiSwati and were digitally recorded.

Table 1: Sampling Strategy			
Group	Total Included	Sampling Strategy	Diversity factors included:
NGO	9	Purposive by research team to maximise diversity	+ Geographic location + Age of organisation + Number of carers + Access to funding
CHW	17	Purposive by research team to maximise diversity	+ Gender + Age + Training background + Caregiving experience
Client	33	Purposive by research team to maximise diversity	+ Gender + Age + Disease + Type of care provided
PCG	30	Purposive by client	

22 follow-up interviews were conducted with eight triads comprised of seven clients, eight PCGs and seven CHWs. Participants were purposively selected for follow-up interviews to explore emerging themes from preliminary interviews. Interviews opened with the reading of a vignette whose characters experienced a similar situation to that encountered by the triad. Participants were asked to reflect on the roles, needs and challenges of the vignette's CHW, client and PCG and to

compare the characters experience to their own. Following the vignette, participants were asked clarity and probing questions based on their preliminary interview. Interviewers specifically explored IEC services provided by CHWs in the home. An example of a translated vignette and associated questions is provided in **Appendix E**.

Figure 1: Organisation of Preliminary Interview Participants



Each triad was given a unique identifier. Clients were labelled C, PCGs were labelled P and CHWs were labelled H. This was done to allow for easy linkage of the various members of a care triad. Some CHWs had multiple clients and, therefore, are a member of multiple triads. For example, CHW1/2 is the CHW for clients 1 and 2 who are supported by PCGs 1 and 2, respectively. This is shown above in **Figure 1**.

Data analysis

All interview recordings were translated and transcribed by a member of the team who conducted the interview. All transcripts were imported into Atlas.ti 6.2.16 (Scientific Software Development, 2010) and read by the primary author twice prior to coding. Data was coded in a systematic manner in which all members of a triad were read using constant comparison to enhance comprehension and facilitate source triangulation. Preliminary coding used an open coding approach in which repeating ideas were identified and coded. These repeating ideas were then organised into themes which informed the theoretical constructs for analysis (Auerbach & Silverstein, 2003). The primary author then discussed these codes with two other members of the research team who concurrently coded the data. The focus of this analysis is on identifying competencies, needs and provision of IEC services.

This article is an analysis of the qualitative data from the mixed methods study entitled “Quality of Care in the Home”. Ethical approval for the study was obtained from the institutional research boards of the University of Cape Town, the University of Witwatersrand, the national Department of Social Development and the provincial Department of Health.

Results

Common narratives

CHWs report a broad range of services and experiences, yet there is a common narrative of the scope and nature of CHW work which emerges from the data. The CHW, 20/21H, typifies this experience and themes are shown in bold:

20/21 started to volunteer at the local clinic in 1990 teaching patients about TB. He volunteered for 12 years and, despite little formal education, developed a substantial knowledge base through a number of trainings and his work at the clinic. Around 2000 he was recruited to be a CHW at a local HBC organisation. As a CHW, he draws upon these **background skills**. He explained “*I knew all these things before I joined the organization. I learnt them while I was still volunteering at the clinic and also by reading many books and pamphlets*”. He has, however, received additional **training from his HBC**.

As a CHW, 20/21H goes house-to-house giving **health talks** and explaining about various illnesses. When he comes across a sick person he will **teach the ill person** about their illness and **motivate clinic access**. Despite basic training on IEC provision, 20/21H has developed his own techniques for knowledge transfer. He explained, “*It’s like a bible you have to go preach that verse and even tomorrow go back to preach the same verse. The person will eventually understand.*” One particular challenge in motivating clinic attendance is the pervasive belief in **traditional medicine** within the community.

In addition to his work with patients, 20/21H also works with the family of the client and **teaches the PCG** how to provide care for the sick person. Finally, 20/21H will sit the entire family down and **mediate between the PCG and the client**. In the process of his work, 20/21H **adapts IEC messages** to fit the local context along with his own personal health beliefs.

CHW 20/21’s services and the value of these services were triangulated through interviews with two of his clients and the PCGs of these clients. The experience of his client, 21C, is shown below:

21C's experience with illness started when her husband and their child became sick and died. When they had been sick 21C **did not understand** what was happening and spent a lot of money on tablets and **traditional care**. 21C started to be sick in 2006 and met the CHW, 20/21H, when he was going house-to-house. 20/21H explained that he **encouraged her to go to the clinic**, but 21C highlighted that her own experience with her husband’s illness was also

a strong motivation for her clinic access. This myriad of influences led 21C to the clinic where she requested an HIV test. 21C tested positive and took classes at the clinic, but **she did not disclose her status to her caretakers**. The clinic instructed 21C to bring a treatment adherence supporter with her to the hospital so she brought her granddaughter (21P) to the clinic, but did not tell her why. 21P only learned from the doctor that her grandmother had HIV and was very upset by the experience.

21C is now doing much better and takes her treatment well. She coped with side effects early on because she had **learned about them**. She then recognised HIV symptoms in her sister and recommended that her sister get tested. Both sisters now collect treatment together. She explains that the CHW checks on her and sometimes brings her fruits.

21C's granddaughter and PCG, 21P, had a similar experience and agreed that the CHW comes to check on her grandmother, but she explained that she has little interaction with him and is unclear on his services. Each of the main themes highlighted by the triad above resonates with the other study participants' experience of IEC services and will serve as the framework for the remainder results section. CHW background skills and training will be presented, followed by the findings on health talks, illness-specific IEC and PCG capacity-building. Next, CHWs mediation in the home and role bridging the divide between the home and the formal health sector will be discussed along with CHWs' encouragement of western medicine over traditional medicine and adaptation of IEC messages. The findings will conclude with exploration of client and care giver perceptions of IEC Roles.

CHW Background Skills

CHWs come to their organisations with a range of skills and experiences which inform their work in the community. Four of the 17 CHWs volunteered at the clinic before becoming HBC CHWs and had years of experience and training to draw upon. Other CHWs learned about illnesses and caretaking through previous experiences as PCGs for ill family members, through their own illness or through other work in the community. One female CHW explained, "*The work that I was doing to help women was similar to working as community care worker*" (33H). For these CHWs, becoming a HBC CHW was generally a formalization of an existing voluntary position.

While some CHWs entered work as a CHW with advanced skills, there are a number who had little formal education or experience, as shown in **Table 2** below. Study participant socio-demographic information is provided in **Appendix F**. All of the CHWs had some form of literacy

for maintaining records, but over half did not complete secondary school. These CHWs were, therefore, dependent on training offered by the HBC organization.

Table 2: Study Participant Summary: CHW Educational Background and Training			
CHW Training	n=17	CHW Education	N=16
Directly Observed Treatment, Short-course for Tuberculosis	8 (47.1)	Primary or Less	3 (18.8)
HIV/AIDS	7 (41.2)	Some Secondary	4 (25.0)
Voluntary Counselling and Testing	6 (35.3)	Adult Basic Education & Training (ABET)	3 (18.8)
HBC	5 (29.4)	Grade 12	5 (31.3)
First Aid	3 (17.7)	Grade 12 +	1 (6.3)
Peer Education	2 (11.8)		
Ancillary Health Care	1 (5.9)		
None	3 (17.7)		

HBC Training

Similar to the diversity in CHW backgrounds, there is substantial differentiation in the training offered to CHWs once they start with HBC organizations. Three CHWs reported no training, while others were able to complete full year courses on HBC. Most CHWs in this study received shorter, intermittent instruction on HIV/AIDS, STIs and TB which were primarily offered by representatives of local governmental departments. The most frequently mentioned training subjects were infectious disease-related with less emphasis placed on non-infectious disease. Trained CHWs relayed information to peers who did not attend, cultivating a culture in which CHWs taught one-another. There is evidence that CHWs valued the trainings and were able to apply lessons learned and recognise illnesses such as TB. One CHW did, however, mention difficulty in understanding training conducted in English.

Despite a variety of training, CHWs generally drew on their existent skills or developed their own techniques for effective IEC service delivery. There was little direct evidence of training on IEC competencies although two CHWs stated that they were trained on peer education. CHWs developed their own methods for teaching patients and families which generally adapted messages to their audience and their perceptions of a family's informational needs. One CHW presented her lessons in stages based on her understanding of a family's health situation:

When I teach about TB today and teach about HIV tomorrow it's because I listened to his responses when I talked to him about TB, and [these responses helped me] to understand that it will be a problem if I don't talk about HIV. You can sometimes tell when you get to a family if something isn't going well. So it's important that I put much emphasis of this matter of HIV to warn them and advise them to use condoms (22/23H).

Thus, the CHW utilised her training of health conditions combined with her knowledge of the local context and the patient's feedback to ensure that appropriate IEC messages were provided.

In addition to targeting messages based on perceived recipient needs, many CHWs emphasised the importance of repetition in knowledge transfer. CHWs acknowledged that, when first approached, many families do not understand them or do not want to listen to their message. In such situations CHWs often teach the message over and over again in order to reach the family.

When we arrive in each and every family we start by teaching them and I do that until she understands, because in a family you can't just arrive and teach them once and they understand. I keep on teaching them and I do not give-up. I was visiting that family and teaching even when she was sick until she understood that she needed to go for testing (24H).

The CHW is able to gauge families' understanding and ensure that families comprehend and apply the lessons. This method does not, however, always work so one CHW reported that she asks other CHWs to assist her when a family doesn't want to listen to her advice.

Health Talks

Provision of "health talks" was mentioned by at least one member of 30 out of the 33 triads. These health talks generally consist of door-to-door visits and campaigns at homes of clients and non-clients to speak with the household members. Central, recurring health talk messages mentioned by members of the triad were:

- Keep your house clean
- Plant a garden
- Eat healthfully
- Get tested for HIV and for TB
- Condomise
- Use gloves when washing an ill person

Health talk subjects are prompted by national or local campaigns or are responsive to perceived family and community needs for food and the high burden of HIV/AIDS. CHWs also explain to households how to access and to properly utilize government documentation and grants.

Despite the pervasiveness of health talks, they appear to primarily serve as a conduit into households rather than as a central service unto itself. One CHW highlighted this and said, “*We find them [patients] by going door to door to teach them about health talk and remind them about the kind of illnesses that are out there nowadays, and ask them if there isn’t a sick person in their homes*” (14/15/16H). Health talks are a non-threatening way to gain access to a family in order to identify clients.

Illness-specific IEC

CHWs identify ill community members in the course of their health talks and through various other referral networks. When a CHW finds such a person they provide IEC specific to the patient's condition. One CHW explained, “*She was sick and she didn’t know why. That is when I found her and motivated her and she understood*” (14/15/16H). In so doing, CHWs help the patient and the patient’s family to understand the patient’s illness and to respond appropriately, including self-care. Self-care IEC was particularly pertinent for patients who lacked PCGs or whose PCG was often away at school or in other areas. One transferred skill mentioned multiple times was the preparation of oral rehydration solution (ORS, called “drips” locally). “*They put drips on me and gave me treatment. They also told me what I should do if I feel it is going to happen again. Ever since then I am able to take care of myself*” (30C).

CHWs provide specific information on a variety of illnesses, but they emphasize the provision of information and support for more stigmatised or misunderstood conditions such as TB and HIV/AIDS. By providing information about illnesses, CHWs try to mitigate stigma within the community. One CHW explained that a PCG lacked information about HIV, but that she was able to explain the modes of transmission of HIV to him.

He also mentioned that [the client] has told people that she would add something to his food in order to make him get infected.... I tried to explain to the father that he would not get contaminated with the disease. I also explained that a person can be infected with HIV if blood passes to another’s body (31/32H).

Even with this knowledge transfer, stigma persisted and the recipient of 31/32H’s advice continued to believe that his daughter would infect him through food and refused to eat any of her cooking. Other CHWs had more success in mitigating stigma and explain that with information families and clients are able to resume normal relations.

[I]n the family when you are sick then you are no longer accepted like before. You become a problem to them, but if there are CHWs visiting the family they teach the family and the family is able to understand the situation of the client. [The CHWs] explain that the problem is only a sickness and so the client is able to feel free (24H).

Despite the ability of CHWs to provide information, there was still confusion on the link between TB and HIV/AIDS, particularly since these illnesses were often found in the same patients.

PCG Capacity-Building

Patient Care

In addition to teaching care recipients about illness and fighting stigma within the home, CHWs utilise their skills and expertise to teach families how to care for the patient.

We always meet this kind of the situation where by the whole family doesn't know how they can help someone who is sick, and so the CHW is able to help those kinds of family by teaching and bringing light to the family... We were trained that the PCG must learn not to give-up and how they must take care of patients and how to bathe them. After bathing them they sit down with them and support them by talking. That's what we then teach PCGs. (12/13H)

The above quote is indicative that CHWs serve almost in a train-the-trainer capacity. The CHW is taught what a PCG must do and then transfers this knowledge onto the PCGs. According to both CHWs and PCGs, PCGs come to the CHW when they have questions and CHWs provide advice and support to enhance PCG care-taking capacity. One CHW explained:

I taught her everything that she needed to know about taking care of her mother because that is what we do. We focus more on teaching the person who isn't ill so they can take better care of the parent. (14/15/16H)

The PCG of this CHW's client affirmed this role and explained, *"When she comes if there is something that I didn't do right, she shows me how to do it properly"* (16P). Triangulation of sources demonstrates that there truly is knowledge transfer occurring in this home which enhances the quality of the care, for which this PCG is grateful.

Universal Precautions

CHWs also enhance PCG capacity to prevent the transmission of infection in homes. The need for open windows in a home with TB along with the high transmissibility of the illness was stressed. Additionally, there is extensive evidence that CHWs promote the use of gloves or plastic bags to cover hands when taking care of patients. Participants generally express gratitude and understanding of these lessons. One client explained that the CHW *"taught us that if someone is*

not feeling well at home or having a running stomach we have to use hands gloves or plastic bags to touch that person to avoid blood contact". This client internalised this message and later said that *"I was also advising her [the PCG] that she doesn't have to touch me without plastic bags on her hands"* (11C). Thus, CHWs are able to help clients and PCGs to understand how to safely provide care for an ill person. It is notable, though, that a different PCG seemed unhappy that she was instructed to use gloves when caring for her mother.

CHW Limitations

Despite evidence of appreciation for CHW IEC messages, limits and misinformation persist. One PCG believed that *"Smoking causes TB because the smoke in your lungs never goes out"* (20P). She sought information from a variety of sources and had re-interpreted them to justify her sentiment that her husband must cease smoking. Participants are therefore not dependent solely on the health messages of CHWs. They sought and gained information from an array of sources including clinics and other formal health services; family; patients; traditional healers, community members, print media (including clinic pamphlets); tv and radio; and from their own caregiving or illness experience.

Mediation within the Home

CHWs also play a central role in facilitating conversation between clients and their families. Many patients, such as 21C, the prototypical client described above, do not discuss their illness with their PCG or with their family. A different PCG explained, *"Both of us don't like talking; we just talk about other things not about this disease [diabetes]"*(6P). Finally, a third participant explained that she only realized why her late husband had temporarily suggested they use condoms once she had tested positive for HIV and learned about condom use. This evidence suggests that communication remains a persistent challenge in the home.

CHWs have the capacity to facilitate communication in the home and break the silence. One client struggled to get her sons to believe that she had HIV and felt it would be good if the CHW would come and teach her children *"that their mother is sick and teach them about HIV; and also to counsel her children to accept the status of their mother."* The client felt that the CHW would be the appropriate person to facilitate this communication because *"they will understand her since she*

has specialised with teaching about HIV” (12C). Yet, the aforementioned client did not actually ask her CHW to perform this task and her sons still did not accept her status.

Bridging the Divide between the Home and the Formal Sector

There is extensive evidence that CHWs mediate between the home and the formal health service. When CHWs arrive in the home and identify a sick person, one of the first things that they do is motivate clinic use. One client explained, *“the CHWs were the first people to suspect that I had TB and referred me to the clinic where I was tested for TB and found to be positive then started treatment” (24C)*. This CHW explained that she was able to recognise the signs of TB from her HBC training. Another client reported that the CHW informed him when there is food (porridge) available at the clinic for patients. There was also substantial evidence of CHWs referring PCGs and clients to other formal sectors such as to the social worker and to Home Affairs to access food, documentation, and grants.

CHWs take action to facilitate access to clinic services. One CHW collected sputum jars from the clinic in order to assist the testing of clients who had symptoms of TB. Through her assistance, these clients were diagnosed with TB. These actions were particularly critical when patients had negative or ineffectual experiences at the clinic and required extra support. One patient who had TB had just returned from the hospital without receiving care. This patient was not tested for TB, despite being symptomatic, so the CHW intervened to have him tested. The man tested positive and was brought back into the formal health system.

Once a client has had a negative experience, they often seek care elsewhere and do not want to return to the clinic. Numerous participants reported that lost patient results, frustrations and confusion are recurrent issues in the formal health sector. CHWs are able to negotiate re-entry of frustrated patients into the system by explaining the health system and by advocating for the patients. One CHW found a patient who was using traditional medicine who had originally gone to the clinic and was never provided with his test results. The patient’s frustration led him to seek alternative care, but the CHW facilitated the patient’s re-entry into formal care. She accompanied the client to the clinic and *“explained [that] he is complaining that he has a long time submitted his sputum samples but he did not get any assistance. They then helped him” (8/9H)*.

CHWs can mitigate health system frustration and improve health care utilization. When presented with a vignette detailing a patient frustrated with the clinic repeatedly taking tests, one CHW emphasized the role that CHWs have in facilitating understanding between clinics and patients. She explained what the CHW should do:

The first most important thing that she [the CHW] should be helping with is counseling her. The second thing that she should be doing is to explain to [the client] that the reason behind the doctors constantly wanting to run some tests on her is that they are trying to find a way to help her. The third thing that she should be doing is to go to the clinic and explain to them about her client's problems. And the clinic will then decide how to handle this issue. (22/23H)

Thus, CHWs enhance patients' understanding of the formal sector and clinics' understanding of patients. Another CHW brings patients to the clinic to ensure that there is effective and honest communication between the patient and the care provider.

If I find a client that is sick but doesn't accept the condition I teach that client. After I teach them, I personally take that client to the clinic just because I can send such client to the clinic but it's not easy to tell the truth about their status and they usually say they have a headache. Then they are given Panado, but in reality the client is very sick so I go with them. When they are given another day to consult I visit the client a day before the day of consulting and remind the client about the day for consulting. The following day I visit him again to ask more and find out if he really went to the clinic. (12/13H)

This CHW ensured that the patient was open with the clinic and assisted him to adhere to formal health sector advice.

CHW mediation does not stop once a patient has successfully accessed the clinic. CHWs support families from initial symptoms to clinic access all the way through to cure or health stabilization.

We do health talks for families with TB, and we also encourage the PCGs to take care of clients and to take them to the hospital for diagnosis. Then we still continue with follow up and support the clients to continue to take TB treatment and we teach the family how to help the clients to take treatment. (24H)

When a patient has returned from the clinic the CHW helps explain formal health instructions, particularly since patients often return confused or with English documents and instructions that they are unable to read. CHWs also teach patients how to take their medical treatment and inform them about common side-effects in order to enhance patient treatment understanding and adherence. There is, however, evidence that some patients still do not understand treatment and continue to have adherence challenges. Patients also continue to seek illness cures and care outside of the formal health system.

Encouragement of Western Medicine over Traditional Medicine

Belief in traditional medicine is pervasive and many patients visit a variety of healers. The families do this for an assortment of reasons including a lack of information about western medicine.

[W]herever we are going we find people that are sick and when we arrive to teach we find that they already went to see the healer. They inform us that they didn't know anything, the only thing they knew about is that these kind of sicknesses can only be taken care of by healers and that the medical doctors can't treat it. So that's whereby I sit with that client and teach them that when they are sick he or she must go to the clinic and test in order to know what kind of sickness he/she might have. (24H)

The client and PCG of 24H confirmed that they had tried traditional medicine because they lacked information on what they should do. CHWs explain to the patients that they need to go to the clinic and about the care which they will receive there. One CHW said, *"We tell him that he must not be told otherwise because there is no traditional healer that is above a doctor, the hospital is the best; even TB is curable now"* (1/2/3H).

CHWs are able to facilitate entry and maintenance in the clinic for some patients, but others persist in using traditional medicine to fulfil unmet needs. Some patients access western medicine, but continue to have interest in traditional medicine as well, and a recurrent message from CHWs was that they should not mix treatments. One CHW explained *that patients "have to choose one thing they think will help them because they might think one of them works better than the other. So they have to use one thing at a time so they can see how it helps them."* (29/30H). It is, however, notable that this CHW didn't explicitly state that western medicine should be used over traditional, but rather that one should be used at a time in order to determine treatment effectiveness. Some patients have re-interpreted the messages and adapted their own understanding as to what is "mixing treatments". One patient explained that she makes sure not to mix her treatments by taking them at different times of the day:

When I go to sleep I take my pills. Since waking up and going there I haven't taken the traditional medication. I will take my pills in the evening. It's not right to mix them together (31C)

Local Adaptation of IEC Messages

CHWs are able to communicate in locally comprehensible language by adapting IEC messages. This local adaptation of IEC is particularly evident regarding traditional health beliefs and

medicine. CHWs incorporate local understanding of illness into their health talks and explain their relation with western illnesses. Our prototypical CHW, 20/21H, explained his response to local beliefs in the traditional illnesses of *Tindzaka* and *Mafulara*,

Most people were defaulting from treatment saying they are not suffering from TB but Tindzaka or Mafulara with the result of that people were dying in large numbers. So we continue giving health talks to the very same people who were sick and most ended up understanding that Tindzaka or Mafulara are more or less the same with TB. (20/21H)

Rather than dismiss the existence of traditional illnesses- which would be antithetical to local perceptions of ill health causation- CHWs explain the relation of *Tindzaka* to TB and advocate formal health care access. Additionally, CHWs do not completely advocate for the disuse of traditional medicine, but rather for clients to use clinics first. Traditional medicine can then be used if western medicine is ineffectual. *“We were already thinking many things like the traditional healers but she [the CHW] said let’s put aside the traditional healer stuff and we must start at the clinic and when the clinic fails we would consider the traditional healer”* (24C). Finally, one CHW said she must ensure that her client adhered to his traditional medicine. CHWs generally advocate for western medicine over traditional medicine, but they are cognisant of the local worldview and temper their messaging to reflect these local beliefs.

In addition to adaptation of IEC to meet local conceptions of illness, CHWs also develop terminology which they perceive as more locally appropriate. The most pervasive example of this is the term TB + (TB plus). CHWs from three organizations in diverse parts of the sub-district used this term- learned during training- to describe patients who were actually or were perceived to be HIV positive. One CHW explained that, *“TB+ is just a term that is used when, for instance, people are sitting with a person who has the TB+ and don’t want her to feel ashamed”* (8/9H). The term is indicative that TB is considered to go hand-in-hand with HIV, but that HIV is still highly stigmatized. CHWs simultaneously try to combat confusion between TB and HIV, *“Most people don’t understand what TB is. When they tell them at the clinic that they have TB they just assume that they have AIDS and never go back to the clinic again. We are teaching them to differentiate TB from AIDS”* (17H).

Client and care giver perceptions of IEC Roles

CHWs clearly provide a number of different non-direct physical care functions in the home and there is substantial evidence that care recipients value these services and follow CHW advice.

When asked what the role was of the CHW, one client said, *“Our relationship is that she was my teacher and if it was not for her I would be dead by now, she is my best friend.”* (25C) This woman prioritized the IEC role of the CHW and its impact on her life. Further evidence of appreciation of the IEC services is that CHWs are considered a central health information resource in the community. When patients have questions about a diversity of health-related topics they often ask their CHW. For example, one client replied that when she had questions about her health she talks to the CHWs:

Just like when I received the treatment for TB, they [the HBC workers] are the ones whom I was talking with to find out whether I can mix the treatments, or if I can take the TB treatment and leave the other treatment [HAART]. (24C)

Clients and PCGs are receptive and responsive to the advice and IEC messages put forth by CHWs and it impacts upon behaviour in the community. *“He is accepting my advice and he also welcomes me when I give him some advice and he does what I tell him to do”* (10/11H).

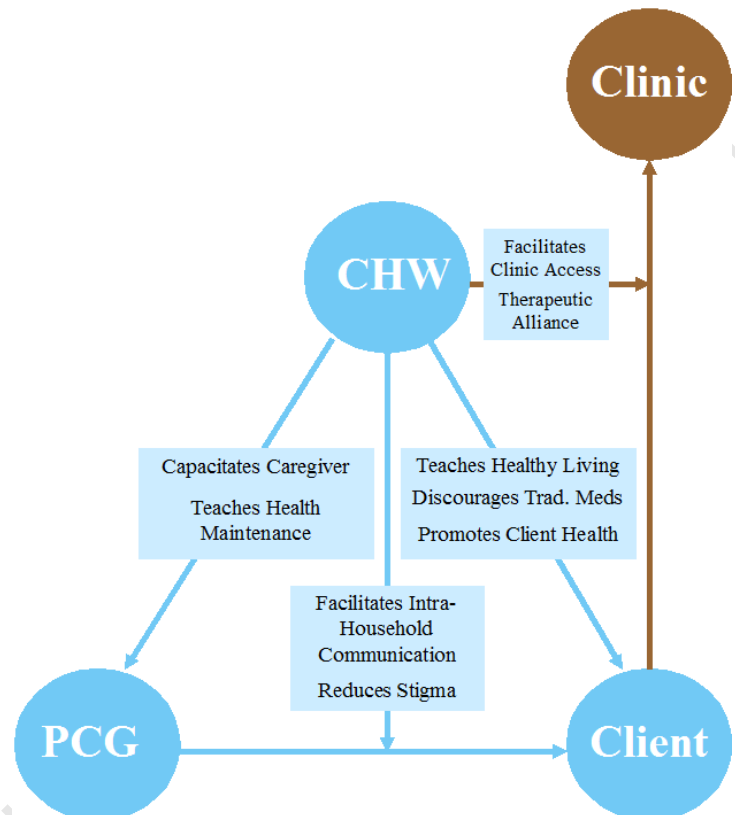
Yet CHW’s advice is not always valued, particularly when the CHWs are young women discussing taboo subjects. One CHW who attempted to teach a large group of women the value of exclusive breastfeeding explained *“that elderly women responded, ‘We are the ones who raised you, and we raised you by feeding you soft porridge. That information about babies not being fed soft porridge is not right, so just keep quiet.’ And in our culture is not proper to argue with the elderly.”* (8/9H). The health talk was rendered ineffective by elderly women effectively silencing the CHWs. CHWs also face taboos against discussion of private, sexual matters, particularly in church-affiliated HBC organisations. One CHW of such an organization explained, *“the people in charge were pastors and the issues of condoms were never mentioned”* (22/23H).

Discussion

There is clear evidence that extensive IEC needs exist within the community and that CHWs have the capacity to address these needs. Despite the diversity, and, at times, paucity of CHW training, as has been reported in other studies (van Pletzen et al., 2009; Friedman, 2005), CHWs draw upon their own experiences and that of their peers to provide a broad array of IEC services in the community. A conceptual diagram of the IEC and mediation role of CHWs is shown below in **Figure 2**. This includes the use of largely organically developed IEC techniques- such as repeatedly “preaching” a message- which facilitate local understanding. CHWs provide general health information that is responsive to the local needs and also illness-specific information which

helps to mitigate stigma within the community and the home. Some CHW messages, however, are contradictory and have the potential to perpetuate stigma and misinformation. For example, CHWs will use the term TB+ to create ambiguity and thus limit the stigma of HIV, but by using the term on “HIV suspects”, CHWs label clients and may cause further confusion between TB and HIV.

Figure 2: CHW IEC and Mediation Roles



A central non-curative service provided by CHWs is support for PCGs’ care-giving and mediation in the home. CHWs are external agents who are able to liaise between family members and to provide objective, informed advice. They also enhance PCG capacity and, therefore, facilitate higher quality care in the home. A qualitative study of the PCGs of clients living with HIV/AIDS conducted in South Africa found that training on optimal caring along with counselling for the family were central needs reported by PCGs (Orner, 2006). In this study site, CHWs are fulfilling these needs and, thereby, helping to enhance PCG and client psychosocial health and wellbeing.

Finally, CHWs are particularly adept at improving health care access and facilitating links between the formal sector and the home. These CHWs possess the “systems knowledge” necessary to help

the community navigate the formal health system and “to broker access to services such as health care or social grants” (Schneider & Lehmann, 2010, p 65). CHWs also facilitate re-entry after patients have been discouraged from using western medicine by negative experiences- as was also reported in a different study conducted in the same study area (Goudge et al., 2009). Additionally, in this former homeland area with a poor history of formal education and a population whose first language is almost entirely Sepedi or Tsonga, CHWs are able to help foster cultural access and bridge linguistic barriers to care. These same barriers have been documented in other South African settings (Crawford, 1999; Deumert, 2010).

The conception of worldviews offers a valuable lens to understand the contribution of CHWs. For health information to be effective it must be comprehensible, adequate and trustworthy (Thiede, 2005). CHWs’ role, both as members of the local community who are responsive to the community, and trained in western notions of illness, allows them to provide trustworthy advice about the formal health sector. They understand the benefits and limitations of both traditional beliefs and western medicine. Although CHWs messages may not be the explicit pro-western medicine IEC promoted by the formal health sector, messages which prioritise western medicine without precluding traditional medicine may be more effective in the local context. However, it is notable that CHWs are generally more critical of traditional medicine, despite patients’ frustrating experiences with their local clinics. This may reflect CHWs’ allegiance to the formal sector.

Conclusion

The findings from this study demonstrate that through adaptation of messages, strong community understanding, and personal relationships, CHWs are currently acting as vital bridges between patients and the formal health care system. It is, therefore, important that this role be protected. The work of CHWs is being formalised and the risk exists that they will lose their foothold in the community. It is imperative that CHWs continue to be drawn from the local community and that preventive and promotive work is supported. This will require adaptation of monitoring and evaluation systems to match the shifting CHW role. Governmental indicators can profoundly influence HBC and CHW functioning in their current prioritisation of services for the ill. Emphasis on non-curative services must be developed which highlight the central role that CHWs play in the home. Support and training for both formal health service workers and CHWs must also be provided which strengthen CHW capacity to serve as the community face of the formal

health services. Such training must include IEC provision tools which incorporate locally adapted methods while eschewing stigmatising adaptations. It is only then that CHWs will be adequately able to adequately serve as teachers who save lives.

Works Cited

- Armon, K., Stephenson, T., MacFaul, R., Eccleston, P., Werneke, U. (2001). An evidence and consensus based guideline for acute diarrhoea management. *Arch Dis Child*, 85(2), 132-42.
- Auerbach, C.F., & Silverstein, L. (2003). *Qualitative Data: an Introduction to Coding and Analysis*. New York: New York UP.
- Boutin-Foster, C., George, K.S., Samuel, T., Fraser-White, M., Brown, H. (2008). Training community health workers to be advocates for health promotion: efforts taken by a community-based organization to reduce health disparities in cardiovascular disease. *J Community Health*, 33(2), 61-8.
- Bushbuckridge Local Municipality. (2009). Integrated Development Plan (Idp) 2009/2010 - 2010/2011 - 2011/2012. Web. 12 Nov. 2010.
<cgta.mpg.gov.za/.../IDPs%202009.../Ehlanzeni%20Converted%20IDPs/Bushbuckridge2009-10.pdf>
- Crawford, A. (1999). "We can't all understand the whites' language": an analysis of monolingual health services in a multilingual society. *Int'l. J. Soc. Lang.*, 136, 27-45.
- Defilippi, K.M., & Cameron, S. (2007). Promoting the Integration of Quality Palliative Care- The South African Mentorship Program. *Journal of Pain and Symptom Management*. (33)5, 552-7.
- Desmond, C., Gow, J., Loening-Voysey, H., Wilson, T., Stirling B. (2002). Approaches to caring, essential elements for a quality service and cost-effectiveness in South Africa. *Evaluation and Program Planning*, 25(4), 447-45.
- Deumert, A. (2010). 'It would be nice if they could give us more language' -- Serving South Africa's multilingual patient base. *Social Science & Medicine*, 71: 53-61.
- DoH (South African Department of Health). (2001). *National Guideline on Home-Based Care/ Community-Based Care*. Compiled By the Directorate: Chronic Diseases, Disabilities and Geriatrics.
- DoH. (2010). Re-engineering Primary Health Care in South Africa. Discussion Document.
- DPLG (South African Department of Provincial and Local Government) & Business Trust. (2007). Nodal Economic Profiling Project: Bushbuckridge Mpumalanga.
- DSD (South African Department of Social Development). (2006). Department of Social Development nodal baseline survey: Bushbuckridge Results. Web. 10 Nov 2010.
<www.sarpn.org.za/.../Bushbuckridge_DSD_nodal_baseline_report.pps>
- Friedman, I. (2005). Community health workers and community caregivers: towards a model of unified practice. In Ijumba P, Padarath A, (Eds.), *South African Health Review 2005*. Durban: Health Systems Trust.
- Goudge, J., Gilson, L., Russell, S., Gumede, T., Mills, A. (2009). Affordability, availability and acceptability barriers to health care for the chronically ill: Longitudinal case studies from South Africa. *BMC Health Services Research*, 9, 75
- Lehmann, U., Sanders D. (2007). *Community health workers: What do we know about them? The state of the evidence on programmes, activities, costs and impact on health outcomes of using community health workers*. Geneva: World Health Organisation.
- Lewin, S., Munabi-Babigumira, S., Glenton, C., Daniels, K., Bosch-Capblanch, X., van Wyk, B.E., Odgaard-Jensen, J., Johansen, M., Aja, G.N., Zwarenstein, M., Scheel, I.B. (2010). Lay health workers in primary and community health care for maternal and child health and the management of infectious diseases. *Cochrane Database of Systematic Reviews* 2010, 3, CD004015. DOI:10.1002/14651858.CD004015.pub3.

- Lurie, M., Pronyk, P., de Moor, E., Heyer, A., de Bruyn, G., Struthers, H., McIntyre, J., Gray, G., Marinda, E., Klipstein-Grobusch, K., Martinson, N. (2008). *J Acquir Immune Defic Syndr*, 47, 484–493.
- Ncama, B.P. (2005). Models of Community/ Home-Based Care for People Living with HIV/AIDS in Southern Africa. *Journal of the Association of Nurses in AIDS Care*, 16(3), 33-40.
- Ndaba-Mbata, R.D. & Seloilwe, E.S. (2000). Home-based care of the terminally ill in Botswana: knowledge and perceptions. *International Nursing Review*, 47, 218-223.
- Nemcek, M.A., Sabatier, R. (2003). State of Evaluation: Community Health Workers. *Public Health Nursing*, 20(4), 260–270.
- Orner, P. (2006). Psychosocial impacts on caregivers of people living with AIDS. *AIDS Care*, 18(3), 236-240.
- Schneider, H., Hlophe, H., & van Rensburg, D. (2008). Community health workers and the response to HIV/AIDS in South Africa: tensions and prospects. *Health Policy and Planning*, 23, 179-187.
- Schneider, H., Lehmann, U. (2010). Lay health workers and HIV programmes: implications for health systems. *AIDS Care*, 22(1), 60-67.
- Schneider, H. (2010). *Mainstreaming HIV and AIDS into the Primary Health Care System: A Review of Current and Potential Community Care Worker Roles; Report to the Department of Health and UNICEF*. Cape Town: Centre for Infectious Diseases Epidemiology and Research. Technical Report.
- Scientific Software Development. (2010). Atlas.ti for Windows, Rel. 6.2, Berlin: Scientific Software Development.
- Thiede, M. (2005). Information and Access to Health Care: Is There a Role for Trust? *Social Science & Medicine* 61.7, 1452-462.
- Uys, L.R. (2002). The practice of community caregivers in a home-based HIV/AIDS project in South Africa. *Journal of Clinical Nursing*, 11, 99-108.
- van Pletzen, E., Colvin, C.J., Schneider, H. (2009). *Community Care Workers in South Africa: Local Practices Case Studies from Nine Provinces*. Cape Town: Centre for Infectious Diseases Epidemiology and Research. Technical Report.
- van Ginneken, N., Lewin, S., Berridge, V. (2010). The emergence of community health worker programmes in the late apartheid era in South Africa: An historical analysis. *Social Science & Medicine*, 71(6-3), 1110–1118.
- Viswanathan, M., Kraschnewski, J., Nishikawa, B., Morgan, L.C., Thieda, P., Honeycutt, A., Lohr, K.N., Jonas, D. (2009). *Outcomes of Community Health Worker Interventions. Evidence Report/Technology Assessment No. 181*. AHRQ Publication No. 09-E014. Rockville, MD: Agency for Healthcare Research and Quality.

Appendix A- Data Collection Tools

Client: Guided Questionnaire

1. What has your experience been with your illness? (Narrative)
2. What services and/or activities are provided to you with regards to your health care? (general and in-home)
3. Why are you being offered these services? How are these services being provided to you? (general and in-home)
4. More specifically, what types of services is _____ (CHW) providing to you? and _____ (PCG)? (Have the client elaborate on the services mentioned)
5. Are things going well in regards to your health care? What are some of the success? (E.g., likes, benefits, appreciates, progress)
6. Are there things that are not going well in regards to your health care? Or Challenges you are experiencing? (E.g., problems, difficulties, hardships, progress)
7. How do you feel about the nature/ state of care you receive?
8. How is your relationship with the PCG? How is your relationship with the CHW? How is your relationship with others involved in your care? (E.g., interactions with community, clinic, home, etc)
9. Do you have any suggestions you would like to share about improving your standard of care? (General and In-home)

Primary Care Giver: Guided Questionnaire

1. How are you related to _____ (client)?
2. What has your experience been with _____ (client's) illness? (Narrative)
3. What are _____ (client's) needs? (General and household health care)
4. What type of care do you provide for them? (General and household health care, explore services and activities)
5. What is your role as PCG? How do you see your role as a PCG?
6. With regards to your experience as a PCG, what things are going well? (E.g., likes, benefits, appreciates, progress)
7. What things are not going well? (E.g., problems, difficulties, hardships, progress)
8. How do you feel about the nature of the care provided by each of the different services providers to _____ (client)? What about the care that you provide?
9. How is your relationship with _____ (client)? How is your relationship with the CHW? How is your relationship with others involved in the care of the client? (E.g., interactions with community, clinic, home, etc)
10. Do you have any suggestions you would like to share about caring for people who are sick in the home? Perhaps regarding needs and services of _____ (client)? and _____ (CHW)?

Community Care Worker: Guided Questionnaire

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 the 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 each CHW these questions once about each of the two clients selected.

9. Tell us about _____ (client 1/ client2)? (Conditions, health needs)
10. How did you find _____ (client 1/ client 2) as your client? (Process)
11. What do you do for _____ (client 1/client 2)? (Number of visits, frequency, services provided)
12. How is _____ (client1/client 2) coping with the illness? What is _____ (client1/client 2) 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)?
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- Information Leaflet

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 Care in the Home in Rural South Africa 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 care worker 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, particularly to understand the quality of care being provided in the home.

The study will be performed in Bushbuckridge only and approximately 75 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 or two occasions, 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 scientific knowledge that may help improve the quality of 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 receive any form of payment for your participation in the study.

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

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, Rose Zulliger, at 082 706 0854.

If you want any information regarding your **rights as a research participant, or complaints regarding this CHRSA 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.

Thank you for your time.

University of Cape Town

Appendix C: Informed Consent Forms

INFORMED CONSENT:

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

I have also received, read and understood the above written information (Participant Information Leaflet and Informed Consent) regarding the Care in the Home 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: Key Literature Review Article Summaries

Article	Key Findings
<p>Campbell, C. & Foulis, C. (2004). Creating contexts for effective home-based care of people living with HIV/AIDS. <i>Curationis</i>, 27(3), 5-14.</p>	<p>This article presents a review of existing research on home-based care in sub-Saharan Africa in order to fill gaps in the research, particularly on community mobilisation. Campbell & Foulis present background information on home-based care, including the factors which led to increased HBC services and assert that the <i>National Guidelines on Home-based Care</i> in South Africa provides only a general outline on the services without explaining how it should be put into practice. The article discusses three forms of participation which are essential for promoting health and wellbeing: grassroots participation in the delivery of formal health services; participation of local people in community-based projects; health-enhancing behaviours; and high levels of community social capital. The authors assert that HBC can potentially incorporate all three of these forms of participation since it uses lay people to offer environments which are conducive to both dignified deaths and enhanced community understanding of HIV and community mobilisation to advocate for the needs of those living with AIDS.</p> <p>The review of existent literature found that most studies on HBC are descriptive in nature; conceptually fragmented yet focus either on the difficulties facing carers or on the challenges of creating conducive environments for various levels of actors within the environment to perform their role. Research shows that individuals are often hindered by a lack of knowledge on how to effectively administer care and by the “traumatic physical and psychological burden of caring for dying people”. Households-level factors are then discussed including how women nearly always carry the heaviest burden of care for PLWHAs. The authors conclude that there is a need for more rigorous understanding of HBC, create linkages or partnerships to address community problems.</p>
<p>Friedman, I. (2005). Community health workers and community caregivers: towards a model of unified practice. In Ijumba P, Padarath A, (Eds.), <i>South African Health Review 2005</i>. Durban: Health Systems Trust.</p>	<p>Friedman defines Community Based Health Workers (CBHW) as all types of community based health workers who carry out health delivery and welfare services in the communities in which they live, are trained in some way, and work in the context of intervention, but have no formal professional background. The history of CBHW is presented as dating back to the 1978 establishment of the Primary Health Care paradigm in the WHO declaration of Alma Ata. CBHWs were first established by NGOs and ‘homeland’ governments under the apartheid regime until national workshops advocating for CBHW support were held from about 1992-4. CBHW were initially envisaged to play a large role in health provision, but after democratic transition resulted in no national programme. In 1996 the DoH delegated the decision on use of CBHW to provincial and district levels. Uncertainty remains about the roles of CBHWs and the challenges from the early 1990s remain largely unmet.</p> <p>Friedman then highlights some of the accomplishments and some of the challenges facing CBHWs. CBHWs differ tremendously, but many have tremendous accomplishments and are valued because they enhance community participation, are excellent health promoters and bring stakeholders into one forum that acts as a core integrative structure around which vertical programmes can rally. One particular success is the cost-effectiveness and high completion rates found amongst DOTS programmes implemented by CHWs. Some of the challenges facing CBHW programmes include competition amongst CBHWs, excessive number of days that CBHWs are expected to work, a large range in the type and amount of training offered, inconsistent support and supervision, weak M&E, transport issues, and inadequate coordination with other sectors including the district health system. The challenge of whether to pay CBHWs is addressed and Friedman concludes that adequate and sustained remuneration is required for effective CBHW programmes. The workers are currently paid by a community-based NGO with state funds. Dependency on the ideal of volunteerism is likened to exploitation of the poor and the value of increasing opportunities for CBHWs to progress in the field is presented.</p> <p>The chapter highlights the need for CBHWs to be recognized as members of the district health team. A model of CHW supervision by Doherty and Coetzee is presented in which CBHW are supported by community based facilitators who report to NGOs. NGOs are held accountable by community health committees and the district health services through technical support and capacity building. The need for continuous, community-based, experiential, accredited training is highlighted. The chapter concludes with recommendations on structures for salary, supervision, accountability, support, alleviation, training, and internal evaluation for CBHW.</p>
<p>Gilson, L., Gill, W., Heggenhougen, K., Owuor-Omondi, L., Perera, M., Ross, D., & Salazar, L. (1989). National Community Health Worker Programs: How Can They</p>	<p>CHW projects expanded dramatically in the 1980s and the study aimed to evaluate the implementation of CHW programs by examining policy, planning, and management in order to suggest improvements within the program. Data collection consisted of a literature review, three case studies and an international workshop.</p> <p>Gilson and colleagues found that many unrealistic expectations of CHW projects were not met, particularly regarding to selection of volunteers by the community, community ownership of the projects, and the role of the volunteers. Volunteers were provided with few opportunities and trainings, yet expected to maintain links with other sectors and act as change agents for their communities. Rather than meeting these expectations, volunteers often were seen as</p>

<p>Be Strengthened?. <i>Journal of Public Health Policy</i>, 10(4), 518-532.</p>	<p>of existing health systems and were largely imposed on communities in response to international emphasis on primary health care in poorly planned ways. Problems identified include problems with training, supervision and support, largely passive community support, all of which raise concerns about the quality of care provided. It was also found that overall costs for effective projects can actually be high, particularly given high attrition rates which require frequent training of volunteers.</p> <p>Gilson highlight the need for communities to know what CHW services include and how to access them. Clear job descriptions and guidelines and systems should be enhanced to strengthen CHW services. Inputs towards supervision and supplies must also be increased in order to enhance the quality of care. Enhanced volunteer reward systems should be considered to boost CHW morale.</p>
<p>Lewin, S., Munabi-Babigumira, S., Glenton, C., Daniels, K., Bosch-Capblanch, X., van Wyk, B.E., Odgaard-Jensen, J., Johansen, M., Aja, G.N., Zwarenstein, M., Scheel, I.B. (2010). Lay health workers in primary and community health care for maternal and child health and the management of infectious diseases. <i>Cochrane Database of Systematic Reviews</i> 2010, 3, CD004015.</p>	<p>This Cochrane review of the effect of lay health workers (LHWs) on maternal and child health with regard to management of infectious diseases included 82 relevant randomised control trials. It is an update on the review in 2005 which focused on the use of LHWs in primary and community health care. The LHW definition used here is similar to that of CHWs used in other articles and includes CHWs. The majority of included articles were based on studies conducted in high-income countries (n=55), and, specifically, with low income groups primarily with the USA. The background summarises the history of LHW around the world and their potential utility in reaching millennium development goals, especially around child health and TB and HIV/AIDS.</p> <p>The included studies provided little information on LHW background and training, but the information that was varied (e.g. 0 to 146 days of training). Overall, the studies appeared to have high risk of bias and be of low quality. The study found that there was moderate evidence that LHWs enhance childhood immunisation uptake, promote breastfeeding initiation (and exclusive breastfeeding) and that they improve pulmonary tuberculosis cure rates. Additionally, the study found moderate evidence that LHW had little or no effect upon TB preventive treatment completion, and there was low evidence that LHWs reduce child morbidity and mortality. Overall, application of the review's findings may be limited given that the studies all detailed interventions and had short follow-up periods and did not provide information on the interventions' links with the formal health sector.</p>
<p>Ncama, B.P. (2005). Models of Community/Home-Based Care for People Living with HIV/AIDS in Southern Africa. <i>Journal of the Association of Nurses in AIDS Care</i>, 16(3), 33-40.</p>	<p>This paper reviews CHBC history and the existing CHBC models operating in southern African countries. The model for PLWHA was initiated in North America and Europe in the late 1980s because in order to provide comprehensive and effective care. Literature suggests that there are two basic forms of caregiving, formal and informal, but it is recognised that families are the first-line providers of care for their members. This is why the article highlights the need for formal mechanisms to assess the strength and limitations of family caregivers and to intervene with support and respite.</p> <p>Formal care has many models, but it can essentially be grouped according to the service models of home-based care and comprehensive home-based care which tend to run by more established NGOs. The models can also be grouped according to structure which are: isolated agencies which usually have no referral system or integration with existing care systems; specialized/private which is typically found mostly in developed countries where specialists care for patients in the home; and collaborative and integrated which involves collaboration between a number of partners and where programmes are integrated into some health services although organisation varies widely. Some collaborative and integrated programs are initiated by the hospital in which volunteers are trained and supported by the hospital, but others are NGO-, FBO-, and CBO-initiated and driven. One challenge facing these latter programs is that volunteers may lack commitment and confidentiality and are at risk of exploitation.</p> <p>The WHO Technical Report highlights the importance of avoiding the danger of HBC being used to “justify abdication of public or government responsibility.” One study of HBC (Seloilwe, 2000) found that the HBC quality was low primarily due to lack of knowledge. HBC within NGOs also face the risk that the projects often lack infrastructure and sometimes capacity. The article concludes that HBC is relatively under-researched in sub-Saharan Africa as the literature identifies services or problems without numbering them or identifying and measuring influencing factors. and family outcomes are also only anecdotally described and actual services needs have not been measured.</p>
<p>Nemcek, M.A., Sabatier, R. (2003). State of Evaluation: Community Health Workers. <i>Public Health Nursing</i>, 20(4), 260-270.</p>	<p>This article summarises the utility of CHWs as peers who bridge between peers in their communities and health care professionals. The article is theoretical and based upon experiences with CHWs within the United States dating back to the 1960s. Recently, there has been renewed interest in CHWs due to the demand to reduce health disparities in a cost-effective way. This is because disadvantaged populations in the USA have poor health outcomes and have trouble accessing formal health care. CHWs are able to facilitate entry to the health system, though, because they are trusted members of the local community. CHWs main contributions are that they are able to facilitate therapeutic alliances (relationships between laypersons and health care professionals), risk reduction through education on prevention, diagnosis and treatment and appropriate health care utilisation (i.e. earlier access, especially to primary care providers rather than emergency care). Despite this critical role, CHWs remain underutilised because they are poorly understood and lack evidence on their effectiveness. This article sought to provide more information on CHWs by summarising the existent literature and by providing quality care indicators for CHW work.</p> <p>CHW care is comprised of community outreach, culturally-sensitive care, health education and counselling.</p>

	<p>advocacy, and, at times, health promotion and lifestyle change. The authors found very little information on CHW selection and outcome evaluation and nothing on standardised CHW structures. The authors did, however, determine quality indicators which can be utilised to determine best practices.</p>
<p>O'Brien, M.J., Squires, A.P., Bixby, R.A., Larson, S.C. (2009). Role Development of Community Health Workers: An Examination of Selection and Training Processes in the Intervention Literature. <i>Am J Prev Med</i>, 37(6S1), S262-9.</p>	<p>This article is a literature review of articles on Community Health Workers within the United States. The authors used a summative content analysis to assess how the selection and training was described within 44 articles previously reviewed. The authors asserted that “omitting CHW selection or training procedures from the published literature obscures central information about the very intervention that is under scientific review and therefore hinders a complete understanding of the findings.” The authors emphasize that the difficult nature of community research and identifying appropriate outcome measures impact the observed efficacy of CHW interventions.</p> <p>Insufficient standardization of selection and training inhibit CHW mainstream acceptance. Only 41% of articles included discussion of CHW selection process and 59% discussed training. Training varied from 5 hours to 6 months and mostly depended on CHW role. Effectiveness of CHWs depends on quality of training they receive and how well they are prepared for their work. There is “heterogeneity in CHW training processes, in stark contrast to the training of the established healthcare workforce... The heterogeneity in CHW training likely produces programs with varying impact and quality.” This lack of standardization can also compromise mainstream acceptance of CHW work within the healthcare workforce. The authors then introduce the following role-outcomes linkages evaluation (ROLE Model) which they propose researchers consider when developing and reporting on HCCW interventions.</p>
<p>Schneider, H., Hlophe, H., & van Rensburg, D. (2008). Community health workers and the response to HIV/AIDS in South Africa: tensions and prospects. <i>Health Policy and Planning</i>, 23, 179-187.</p>	<p>This article summarises some of the key features of the South African CHW program using authors' experience with the rollout of ART in a South African province. The history of South Africa's comprehensive response to HIV/AIDS is first explained. The state began to support NGOs employing home- and community-based carers in the mid-1990s. Recent years have seen a rapid expansion in HIV/AIDS funding and programmes which led to a dramatic increase in community-based carers. This increase was largely a response to the health worker shortage rather than for ideological reasons and “massive training of community-based workers” was identified as a fast step towards achieving the Millennium Development Goals.</p> <p>This paper defined CHW as “local inhabitants given a limited amount of training to provide specific basic health, reproductive and nutrition services to the members of their surrounding communities.” The dramatic increases in CHW numbers and government and donor expenditure are detailed along with key policy developments. The government's preferred model of service delivery was a government-NGO partnership in which NGOs receive government grants to employ the CHWs. Another key policy feature highlighted is that the national policy developed organically and provides an overarching framework concept yet it allows for interpretation.</p> <p>This study is part of a larger, longitudinal project documenting the rollout of ART within the Free State province. A literature review was followed by 3 visits over 2 years to each of the first 16 health centres in the Free State province. These visits all consisted of a full inventory of CHWs and training and the two latter visits included semi-structured interviews with the CHWs involving 231, and 182 CHWs. Separate group interviews were also conducted with nurses on CHWs. Findings included an average of 14 CHW per a facility of whom 92% were female. They found a small, more-or-less stable core of CHWs with high turnover rates outside of this core group. CHWs grew into the role of primary communication with patients whereas nurses limited their tasks to more technical endeavours. The majority of nurses were positive about the contributions made by CHWs in their clinics, yet there was a high level of job dissatisfaction amongst the CHWs themselves. CHWs felt undervalued, and that they lacked recognition for their contributions and were exploited by not receiving benefits such as leave, maternity benefits, and pension. They viewed their work as a way to keep busy or as a stepping-stone to formal employment and they developed professional identities. Study recommendations included improving working conditions and basic entitlements of CHWs and accepting a high degree of turnover as a CHW position is not a career endpoint. The authors conclude by stressing the need for more empirical evidence on the problems and contributions made by national CHW programmes.</p>
<p>Schneider, H., Lehmann, U. (2010). Lay health workers and HIV programmes: implications for health systems. <i>AIDS Care</i>, 22(1), 60-67.</p>	<p>This article is a review of the impact of the increase in funding in the context of HIV on health systems in the developing world. Schneider and Lehmann examine the growth in LHWs and its implications for health systems in the developing world, specifically using South Africa as a case. There has been an increase in donor and in governmental AIDS funding in South Africa along with an increase in LHWs as part of these AIDS programmes (from 2000 onwards). In South Africa, approximately 65,000 of these workers exist which is greater than the number of PHC providers and professional nurses. This growth has been organic and unregulated and LHWs fill a variety of roles with substantial variation between provinces. NGOs have filled gaps left by the formal health system and care has been shifted from the formal sector to the home. This development has been accompanied by myriad challenges around remuneration, integration with the health system, and LHW training and management.</p> <p>LHW history is addressed and Schneider and Lehmann explain that the increase in LHW interest is now driven by the need for an available, inexpensive workforce to fill disease-specific roles. Most LHWs were TB or HIV specific. There is a trend towards more generalist care including IMCI. The origins of three forms of LHW, HBC, lay counsellors</p>

	<p>DOTS are discussed. HBC originated as a way to shift palliative care from the overstretched hospitals to the home. In South Africa, predominantly females took care of their dying family members. Lay counsellors emerged from a more psychosocial approach in which counsellors form the basis of VCT and ART patient preparation/ adherence programmes. These lay counsellors represent 10% of the lay health workforce.</p> <p>Policies are now being developed at a national level which are ambiguous (LHW remains on the periphery of the formal system, yet central to its functioning), but have important implications for LHWs. There is now a move to formalise LHW workers which will be challenging in light of their complex and heterogeneous roles both in South Africa and the world.. Schneider and Lehmann call for more research on the various ways that LHWs are involved in the formal health sector and particularly on the actual safety and effectiveness of the work which they are doing.</p>
<p>Thiede, M. (2005). Information and Access to Health Care: Is There a Role for Trust? <i>Social Science & Medicine</i> 61.7, 1452-462.</p>	<p>This article looked at the role that trust plays in affecting demand for health care. The paper emphasises that communication strategies using interactive methods can help enhance access to care. Access is defined as freedom of choice (both the “social possibility <i>and</i> the individual ability to give direction to one’s will to use health services”). Health information creates health knowledge and is a “good provided by the health system.” The impact of information on health behaviour, however, impossible to measure (i.e. how do we know what really prompted a person to use health services) and the factors are manifold. It is also consumed and processed differently by different people. For health information to be effective, it must be comprehensible, adequate and trustworthy. “The character of disease is best understood by an individual who communicates within the appropriate cultural context of her lifeworld. The same is true for the recognition of need for treatment.”</p> <p>Trust affects whether patients utilise provided information and is, therefore, an imperative component for health information services to be effective. It is not sufficient for health policies to merely provide health care, but they must involve the development of trust and enhancement of individuals’ capabilities through engagement with community health workers. Trust is generated through communicative interaction and is also a product of the process. “Information stimulates health behaviour by making the objective choice set transparent to the individual and granting her the autonomous choice.”</p> <p>Lifeworld is “a sphere of inter-subjectively shared assumptions and perceptions of the environment in which health communication processes are embedded (Habermas, 1984, 1989)” Thiede and McIntyre quote Habermas “<i>the sphere of shared cultural knowledge, valid norms and accountable motivations</i>”. “Health systems and the community form overlapping lifeworlds... the greater the overlap between the two lifeworlds, the more preconditions for universal health care are fulfilled.”</p>
<p>Uys, L.R. (2002). The practice of community caregivers in a home-based HIV/AIDS project in South Africa. <i>Journal of Clinical Nursing</i>, 11, 99-108.</p>	<p>Uys sought to describe the work of community caregivers (CCGs) by visiting seven sites which were implementing the Integrated Community-based Home Care model. Uys described the basics of the ICHC model which emphasizes a continuum of care amongst service-providers through the use of two CCGs who are trained for their role in home-based HIV/AIDS care. Her particular questions were CCGs perceptions of their work, what their work entailed, the intensity and form of care provided and the supervision received. Uys found that the CCGs were generally satisfied with their work, despite challenges which included the large economic needs of their communities, safety risks when working with some clients, difficulty asserting themselves when working with other care network professionals, a lack of respect for their work by the formal health sector. The CCGs felt they were making a difference and the PWAs supported this notion, saying that the CCGs were very successful in enhancing the human dignity of PWAs. The study found that the most common form of care was counselling and information (94%) followed by symptom control (68%), both of which were mentioned as useful services by the PWAs and carers.</p>
<p>Viswanathan, M., Kraschnewski, J., Nishikawa, B., Morgan, L.C., Thieda, P., Honeycutt, A., Lohr, K.N., Jonas, D. (2009). <i>Outcomes of Community Health Worker Interventions. Evidence Report/Technology Assessment No. 181</i>. AHRQ Publication No. 09-E014. Rockville, MD: Agency for Healthcare Research and Quality.</p>	<p>This systematic review of CHW interventions sought to determine CHWs characteristics, CHW intervention characteristics, cost-effectiveness and outcomes along with CHW training characteristics. This is because CHWs are a key recommendation for reducing health disparities in the USA. The review included 53 studies focused on CHW intervention characteristics and outcomes, 6 on cost-effectiveness (insufficient for analysis) and 9 on CHW training (insufficient evidence). The review found little evidence that CHW interventions improve participant knowledge relative to control approaches (from five studies), mixed evidence on CHW ability to create behaviour change or improve health. The review found a low/ moderate level of evidence on CHW ability to facilitate appropriate health care utilisation and the effectiveness varied across different health interventions. The authors concluded that CHWs can be effective in underserved populations, dependent on health condition. They found insufficient and inadequate evidence in many areas of CHW work. One notable point from the discussion was, “CHWs, by virtue of their role as a bridge to the health care system, can help to disseminate widely efficacious interventions to populations that rarely benefit from health care advances.”</p>

Appendix E: Sample Follow-up vignette

I am now going to tell you a story about a family to try to learn from you what you think should be done to help this family. There is a family where the mother, Bongiwe, started to feel ill so she decided to go to see the traditional healer. Bongiwe didn't feel any better with the muthi so she decided to go to the clinic where they found that she had HIV. Bongiwe took their treatment, but still didn't feel any better. The clinic later said that Bongiwe had TB and gave her treatment. Bongiwe's mother didn't care for her at first, but later she decided to help to take care of her when she was feeling sick. At the clinic they gave her treatment and Bongiwe started to feel better, A CHW in the community would come to visit Bongiwe and check that she took her treatment and would visit with her. Bongiwe is feeling much better now.

Do you think that the CHW should continue to work with the family the way she does? What role do you think the CHW is playing in the family?

What do you think some challenges might be for Bongiwe's daughter? What should he do to help Bongiwe? Do you face any of these challenges?

What problems do you think that Bongiwe might have?

Do you think the story of Bongiwe and her family is like the story of your family at all? How is your family like Bongiwe's? How is your family different?

Appendix F: Study Participant Summary

Study Participant Demographic Characteristics					
Variable	n (%)	Variable	n (%)	Variable	n (%)
CHWs	17	Clients	33	PCGs	30
Male	1 (5.9)	Male	14 (42.4)	Male	5 (16.7)
Female	16 (94.1)	Female	19 (57.6)	Female	25 (83.3)
Age	16	Age	29		
21-30	5 (31.3)	21-30	4 (13.8)		
31-40	4 (25.0)	31-40	6 (20.7)		
41-50	3 (18.8)	41-50	3 (10.3)		
51-60	1 (6.3)	51-60	6 (20.7)		
61-70	3 (18.8)	61-70	4 (13.8)		
70+	0 (0.00)	70+	6 (20.7)		
Education	16	Reason for Care	33	Relation to Client	30
Primary or Less	3 (18.8)	HIV/AIDS	14 (42.4)	Wife	7 (23.3)
Some Secondary	4 (25.0)	TB	7 (21.2)	Husband	1 (3.3)
Adult Basic Education & Training	3 (18.8)	High Blood Pressure	5 (15.2)	Mother	3 (10.0)
Grade 12	5 (31.3)	Diabetes	3 (9.1)	Father	2 (6.7)
Grade 12 +	1 (6.3)	Asthma	1 (3.0)	Sister	1 (3.3)
		Body Pain	4 (12.1)	Brother	1 (3.3)
Training	17	Stroke	1 (3.0)	Daughter	7 (23.3)
DOTS	8 (47.1)	Hyper-tension	1 (3.0)	Son	1 (3.3)
HIV/AIDS	7 (41.2)	Cancer	1 (3.0)	Daughter-in-Law	1 (3.3)
VCT	6 (35.3)	Malaria	1 (3.0)	Sister-in-Law	1 (3.3)
HBC	5 (29.4)	Herpes	1 (3.0)	Granddaughter	2 (6.7)
First Aid	3 (17.7)	Disabled	2 (6.1)	Grandson	1 (3.3)
Peer Education	2 (11.8)			Cousin	1 (3.3)
Ancillary Health Care	1 (5.9)			Neighbour	1 (3.3)
None	3 (17.7)				
*DOTS= Directly Observed Treatment, Short-course for Tuberculosis; VCT= Voluntary Counselling and Testing for HIV					

Appendix D: Key Literature Review Article Summaries

Article	Key Findings	Applicability
<p>Campbell, C. & Foulis, C. (2004). Creating contexts for effective home-based care of people living with HIV/AIDS. <i>Curationis</i>, 27(3), 5-14.</p>	<p>This article presents a review of existing research on home-based care in sub-Saharan Africa in order to highlight gaps in the research, particularly on community mobilisation. Campbell & Foulis present background information on home-based care, including the factors which led to increased HBC services and assert that the <i>National Guidelines on HBC</i> in South Africa provides only a general outline on the services without explaining how it should be put into practice. The article discusses three forms of participation which are essential for promoting health and wellbeing: grassroots participation in the delivery of formal health services; participation of local people in community-based projects to promote health-enhancing behaviours; and high levels of community social capital. The authors assert that HBC can potentially incorporate all three of these forms of participation since it uses lay people to offer environments which are conducive to both dignified deaths and enhanced community understanding of HIV and community mobilisation to advocate for the needs of those living with AIDS.</p> <p>The review of existent literature found that most studies on HBC are descriptive in nature; conceptually and methodologically fragmented yet focus either on the difficulties facing carers or on the challenges of creating contexts that enable various levels of actors within the environment to perform their role. Research shows that individuals are “hindered by a lack of knowledge” on how to effectively administer care and by the “traumatic physical and psychological effects of caring for dying people”. Households-level factors are then discussed including how women nearly always carry the heaviest burden of care for PLWHAs. The authors conclude that there is a need for more rigorous understanding of how to create linkages or partnerships to address community problems.</p>	<p>This article provides an overview of HBC utility, as found in the literature. It provides a useful critique</p>
<p>Friedman, I. (2005). Community health workers and community caregivers: towards a model of unified practice. In Ijumba P, Padarath A, (Eds.), <i>South African Health Review 2005</i>. Durban: Health Systems Trust.</p>	<p>Friedman defines Community Based Health Workers (CBHW) as all types of community based health workers who carry out health delivery and welfare services in the communities in which they live, are trained in some way in the context of intervention, but have no formal professional background. The history of CBHW is presented as dating back to the 1978 establishment of the Primary Health Care paradigm in the WHO declaration of Alma Ata. CBHWs were operated by NGOs and ‘homeland’ governments under the apartheid regime until national workshops advocating for CBHW formal support were held from about 1992-4. CBHW were initially envisaged to play a large role in health provision, but the 1994 democratic transition resulted in no national programme. In 1996 the DoH delegated the decision on use of CBHW to the provincial and district levels. Uncertainty remains about the roles of CBHWs and the challenges from the early 1980s remain largely unmet.</p> <p>Friedman then highlights some of the accomplishments and some of the challenges facing CBHWs. CBHWs differ tremendously, but many have tremendous accomplishments and are valued because they enhance community participation, are excellent health promoters and bring stakeholders into one forum that acts as a core integrative process around which vertical programmes can rally. One particular success is the cost-effectiveness and high completion rates found amongst DOTS programmes implemented by CHWs. Some of the challenges facing CBHW programmes are competition amongst CBHWs, excessive number of days that CBHWs are expected to work, a large range in the quality and amount of training offered, inconsistent support and supervision, weak M&E, transport issues, and inadequate linkages with other sectors including the district health system. The challenge of whether to pay CBHWs is addressed and Friedman concludes that adequate and sustained remuneration is required for effective CBHW programmes. The workers should be paid by a community-based NGO with state funds. Dependency on the ideal of volunteerism is likened to exploitation of the poor and the value of increasing opportunities for CBHWs to progress in the field is presented.</p> <p>The chapter highlights the need for CBHWs to be recognized as members of the district health team. A model of CHW supervision by Doherty and Coetzee is presented in which CBHW are supported by community based facilitators who report to NGOs. NGOs are held accountable by community health committees and the district health services provide technical support and capacity building. The need for continuous, community-based, experiential, accredited trainings is</p>	<p>This chapter provides very valuable insight into the history of CBHW in South Africa along with other fundamentals of CBHW programmes. The discussion of remuneration for CBHWs is both bold and insightful and the model presented on supervision is useful. Some weaknesses within the chapter include a failure to adequately describe models’ usage and also to explain the methodology used</p>

	highlighted. The chapter concludes with recommendations on structures for salary, supervision, accountability, poverty-alleviation, training, and internal evaluation for CBHW.	to inform the chapter.
Gilson, L., Gill, W., Heggenhougen, K., Owuor-Omondi, L., Perera, M., Ross, D., & Salazar, L. (1989). National Community Health Worker Programs: How Can They Be Strengthened?. <i>Journal of Public Health Policy</i> , 10(4), 518-532.	<p>CHW projects expanded dramatically in the 1980s and the study aimed to evaluate the implementation of the CHW programs by examining policy, planning, and management in order to suggest improvements within the programs. Data collection consisted of a literature review, three case studies and an international workshop.</p> <p>Gilson and colleagues found that many unrealistic expectations of CHW projects were not met, particularly in regards to selection of volunteers by the community, community ownership of the projects, and the role of the volunteers. Volunteers were provided with few opportunities and trainings, yet expected to maintain links with other sectors and to act as change agents for their communities. Rather than meeting these expectations, volunteers often were seen as extensions of existing health systems and were largely imposed on communities in response to international emphasis on primary health care in poorly planned ways. Problems identified include problems with training, supervision and support, and largely passive community support, all of which raise concerns about the quality of care provided. It was also found that overall costs for effective projects can actually be high, particularly given high attrition rates which require frequent training of volunteers.</p> <p>Gilson highlight the need for communities to know what CHW services include and how to access them. CHWs job descriptions and guidelines and systems should be enhanced to strengthen CHW services. Inputs towards supervision and supplies must also be increased in order to enhance the quality of care. Enhanced volunteer reward systems should also be considered to boost CHW morale.</p>	This article sheds light on problems faced by CHW projects historically. It highlights that many contemporary challenges have persisted for decades.
Lewin, S., Munabi-Babigumira, S., Glenton, C., Daniels, K., Bosch-Capblanch, X., van Wyk, B.E., Odgaard-Jensen, J., Johansen, M., Aja, G.N., Zwarenstein, M., Scheel, I.B. (2010). Lay health workers in primary and community health care for maternal and child health and the management of infectious diseases. <i>Cochrane Database of Systematic Reviews</i> 2010, 3, CD004015.	<p>This Cochrane review of the effect of lay health workers (LHWs) maternal and child health with regards to the management of infectious diseases included 82 relevant randomised control trials. It is an update on the review conducted in 2005 which focused on the use of LHWs in primary and community health care. The LHW definition used here is similar to that of CHWs used in other articles and includes CHWs. The majority of included articles were based on studies conducted in high-income countries (n=55), and, specifically, with low income groups primarily with the USA. The review background summarises the history of LHW around the world and their potential utility in reached millennium development goals, especially around child health and TB and HIV/AIDS.</p> <p>The included studies provided little information on LHW background and training, but the information provided was varied (e.g. 0 to 146 days of training). Overall, the studies appeared to have high risk of bias and be of low quality. The study found that there was moderate evidence that LHWs enhance childhood immunisation uptake, promote breastfeeding initiation (and exclusive breastfeeding) and that they improve pulmonary tuberculosis cure rates. Additionally, the study found moderate evidence that LHW had little or no effect upon TB preventive treatment completion, and there was low evidence that LHWs reduce child morbidity and mortality. Overall, application of the review's findings may be limited given that the studies all detailed interventions and had short follow-up periods and did not provide information on the interventions' links with the formal health sector.</p>	This study was rigorously conducted and it highlights some of the successful applications of CHWs, although the utility of these findings in a non-intervention-based, African context is unclear.
Ncama, B.P. (2005). Models of Community/Home-Based Care for People Living with HIV/AIDS in Southern Africa. <i>Journal of the Association of Nurses in AIDS Care</i> , 16(3), 33-40.	<p>This paper reviews CHBC history and the existing CHBC models operating in southern African countries. HBC for PLWHA was initiated in North America and Europe in the late 1980s because in order provide comprehensive and cost-effective care. Literature suggests that there are two basic forms of caregiving, formal and informal, but it is recognised that families are the first-line providers of care for their members. This is why the article highlights the need for mechanisms to assess the strength and limitations of family caregivers and to intervene with support and respite, as needed.</p> <p>Formal care has many models, but it can essentially be grouped according to the service models of home visiting and comprehensive home-based care which tend to run by more established NGOs. The models can also be grouped according to structure which are: isolated agencies which usually have no referral system or integration with existing health care systems; specialized/private which is typically found mostly in developed countries where specialists care for PLWHA in the home; and collaborative and integrated which involves collaboration between a number of partners and are the programmes are integrated into some health services although organisation varies widely. Some collaborative and</p>	The article reviews the current literature on HBC and the two mechanisms discussed for looking at models are useful. The section on C/HBC in SA should have evaluated the

	<p>integrated programs are initiated by the hospital in which volunteers are trained and supported by the hospital, but most are NGO-, FBO-, and CBO-initiated and driven. One challenge facing these latter programs is that volunteers may lack commitment and confidentiality and are at risk of exploitation.</p> <p>The WHO Technical Report highlights the importance of avoiding the danger of HBC being used to “justify abdication of public or government responsibility.” One study of HBC (Seloilwe, 2000) found that the HBC quality of care was low primarily due to lack of knowledge. HBC within NGOs also face the risk that the projects often lack infrastructure and sometimes capacity. The article concludes that HBC is relatively under-researched in sub-Saharan Africa as most literature identifies services or problems without numbering them or identifying and measuring influencing factors. Patient and family outcomes are also only anecdotally described and actual services needs have not been measured.</p>	<p>experiences in terms to the models discussed earlier in the paper in order to expand upon the frameworks.</p>
<p>Nemcek, M.A., Sabatier, R. (2003). State of Evaluation: Community Health Workers. <i>Public Health Nursing</i>, 20(4), 260–270.</p>	<p>This article summarises the utility of CHWs as peers who bridge between peers in their communities and health professionals. The article is theoretical and based upon experiences with CHWs within the United States dating back to the 1960s. Recently, there has been renewed interest in CHWs due to the demand to reduce health disparities in a cost-effective way. This is because disadvantaged populations in the USA have work health outcomes and have trouble accessing formal health care. CHWs are able to facilitate entry to the health system, though, because they are trusted members of the local community. CHWs main contributions are that they are able to facilitate therapeutic alliance (better relationships between laypersons and health care professionals), risk reduction through education on prevention, early diagnosis and treatment and appropriate health care utilisation (i.e. earlier access, especially to primary care providers rather than emergency care). Despite this critical role, CHWS remain underutilised because they are poorly understood and lack evidence on their effectiveness. This article sought to provide more information on CHWs by summarising the existent literature and by providing quality care indicators for CHW work.</p> <p>CHW care is comprised of community outreach, culturally-sensitive care, health education and counselling, health advocacy, and, at times, health promotion and lifestyle change. The authors found very little information on CHW process and outcome evaluation and nothing on standardised CHW structures. The authors did, however, determine quality care indicators which can be utilised to determine best practices.</p>	<p>This article provides a model from which to consider the role of CHWs as mediators and also highlights key quality of care indicators for their future utilisation.</p>
<p>O’Brien, M.J., Squires, A.P., Bixby, R.A., Larson, S.C. (2009). Role Development of Community Health Workers: An Examination of Selection and Training Processes in the Intervention Literature. <i>Am J Prev Med</i>, 37(6S1), S262-9.</p>	<p>This article is a literature review of articles on Community Health Workers within the United States. The authors used a summative content analysis to assess how the selection and training was described within 44 articles previously reviewed. The authors asserted that “omitting CHW selection or training procedures from the published literature neglects central information about the very intervention that is under scientific review and therefore hinders a complete understanding of the findings.” The authors emphasize that the difficult nature of community research and identification of appropriate outcome measures impact the observed efficacy of CHW interventions.</p> <p>Insufficient standardization of selection and training inhibit CHW mainstream acceptance. Only 41% of articles included discussion of CHW selection process and 59% discussed training. Training varied from 5 hours to 6 months and mostly depended on CHW role. Effectiveness of CHWs depends on quality of training they receive and how well they are prepared for their work. There is “heterogeneity in CHW training processes, in stark contrast to the training of the established healthcare workforce... The heterogeneity in CHW training likely produces programs with varying intensity and quality.” This lack of standardization can also compromise mainstream acceptance of CHW work within the formal healthcare workforce. The authors then introduce the following role-outcomes linkages evaluation (ROLE Model) which they propose researchers consider when developing and reporting on HCCW interventions.</p>	<p>The article provides an overview of CHW training in the USA and highlights research article gaps and provides a useful model.</p>
<p>Schneider, H., Hlophe, H., & van Rensburg, D. (2008). Community health workers and the response to HIV/AIDS in South Africa: tensions and</p>	<p>This article summarises some of the key features of the South African CHW program using authors’ experience with the rollout of ART in a South African province. The history of South Africa’s comprehensive response to HIV/AIDS is first explained. The state began to support NGOs employing home- and community-based carers in the mid-1990s. Recent years have seen a rapid expansion in HIV/AIDS funding and programmes which led to a dramatic increase in lay carers. This increase was largely a response to the health worker shortage rather than for ideological reasons and the “massive training of community-based workers” was identified as a fast step towards achieving the Millennium</p>	<p>This article provides a good overview of CHW history and use in the context of HIV.</p>

<p>prospects. <i>Health Policy and Planning</i>, 23, 179-187.</p>	<p>Development Goals.</p> <p>This paper defined CHW as “local inhabitants given a limited amount of training to provide specific basic health and nutrition services to the members of their surrounding communities.” The dramatic increases in CHW numbers and government and donor expenditure are detailed along with key policy developments. The government’s preferred model of service delivery was a government-NGO partnership in which NGOs receive government grants to employ the CHWs. Another key policy feature highlighted is that the national policy developed organically and provides an overarching concept yet it allows for interpretation.</p> <p>This study is part of a larger, longitudinal project documenting the rollout of ART within the Free State. A literature review was followed by 3 visits over 2 years to each of the first 16 health centres in the Free State providing ART. These visits all consisted of a full inventory of CHWs and training and the two latter visits included semi-structured group interviews with the CHWs involving 231, and 182 CHWs. Separate group interviews were also conducted with facility nurses on CHWs. Findings included an average of 14 CHW per a facility of whom 92% were female. They found a more-or-less stable core of CHWs with high turnover rates outside of this core group. CHWs grew into the role of communication with patients whereas nurses limited their tasks to more technical endeavours. The majority of nurses were positive about the contributions made by CHWs in their clinics, yet there was a high level of job dissatisfaction amongst the CHWs themselves. CHWs felt undervalued, and that they lacked recognition for their contributions and were exploited by not receiving benefits such as leave, maternity benefits, and pension. They viewed their work as a way to keep busy or as a stepping-stone to formal employment and they developed professional identities. Study recommendations included improving working conditions and basic entitlements of CHWs and accepting a high degree of turnover as a CHW position is not a career endpoint. The authors conclude by stressing the need for more empirical evidence on the problems and contributions made by national CHW programmes.</p>	
<p>Schneider, H., Lehmann, U. (2010). Lay health workers and HIV programmes: implications for health systems. <i>AIDS Care</i>, 22(1), 60-67.</p>	<p>This article is a review of the impact of the increase in funding in the context of HIV on health systems around the world. Schneider and Lehmann examine the growth in LHWs and its implications for health systems in the developing world, specifically using South Africa as a case. There has been an increase in donor and in governmental AIDS-related funding in South Africa along with an increase in LHWs as part of these AIDS programmes (from 2000 onwards). Within South Africa, approximately 65,000 of these workers exist which is greater than the number of PHC providers and professional nurses. This growth has been organic and unregulated and LHWs fill a variety of roles with substantial variation between provinces. NGOs have filled gaps left by the formal health system and care has been shifted from the formal sector to the home. This development has been accompanied by myriad challenges around remuneration, integration with the health system, and LHW training and management.</p> <p>LHW history is addressed and Schneider and Lehmann explain that the increase in LHW interest is now related to the need for an available, inexpensive workforce to fill disease-specific roles. Most LHWs were TB or HIV specific, but there is a trend towards more generalist care including IMCI. The origins of three forms of LHW, HBC, lay counselling and DOTS are discussed. HBC originated as a way to shift palliative care from the overstretched hospitals to the home where predominantly females took care of their dying family members. Lay counsellors emerged from a more psychological basis in which counsellors form the basis of VCT and ART patient preparation/ adherence programmes. These lay counsellors represent 10% of the lay health workforce.</p> <p>Policies are now being developed at a national level which are ambiguous (LHW remains on the periphery of the formal system, yet central to its functioning), but have important implications for LHWs. There is now a move to formalise LHW workers which will be challenging in light of their complex and heterogeneous roles both in South Africa and around the world.. Schneider and Lehmann call for more research on the various ways that LHWs are involved in the formal health sector and particularly on the actual safety and effectiveness of the work which they are doing.</p>	<p>This article provides insight into the development of LHW roles within South Africa and into the history of the cadre in the country. It also poses key questions on the role of lay health workers within the formal health system.</p>

<p>Thiede, M. (2005). Information and Access to Health Care: Is There a Role for Trust? <i>Social Science & Medicine</i> 61.7, 1452-462.</p>	<p>This article looked at the role that trust plays in affecting demand for health care. The paper emphasises that communication strategies using interactive methods can help enhance access to care. Access is defined as freedom to use (both the “social possibility <i>and</i> the individual ability to give direction to one’s will to use health services”). Health information creates health knowledge and is a “good provided by the health system.” The impact of information is, however, impossible to measure (i.e. how do we know what really prompted a person to use health services) and its effects are manifold. It is also consumed and processed differently by different people. For health information to be effective it must be comprehensible, adequate and trustworthy. “The character of disease is best understood by an individual if communicated within the appropriate cultural context of her lifeworld. The same is true for the recognition of need for treatment.”</p> <p>Trust affects whether patients utilise provided information and is, therefore, and imperative component for information services to be effective. It is not sufficient for health policies to merely provide health scare, but they must also involve the development of trust and enhancement of individuals’ capabilities through engagement with communities. Trust is generated through communicative interaction and is also a product of the process. “Information stimulates access by making the objective choice set transparent to the individual and granting her the autonomous choice.”</p> <p>Lifeworld is “a sphere of inter-subjectively shared assumptions and perceptions of the environment in which communication processes are embedded (Habermas, 1984, 1989)” Thiede and McIntyre quote Habermas “<i>the sphere of shared cultural knowledge, valid norms and accountable motivations</i>”. “Health systems and the community form overlapping lifeworlds... the greater the overlap between the two lifeworlds, the more preconditions for universal access are fulfilled.”</p>	<p>This article provides insight into health information and health access. The conception of worldviews provides a very meaningful framework for considering the roles of CHWs.</p>
<p>Uys, L.R. (2002). The practice of community caregivers in a home-based HIV/AIDS project in South Africa. <i>Journal of Clinical Nursing</i>, 11, 99-108.</p>	<p>Uys sought to describe the work of community caregivers (CCGs) by visiting seven sites which were implementing the Integrated Community-based Home Care model. Uys described the basics of the ICHC model which emphasizes a continuum of care amongst service-providers through the use of two CCGs who are trained for three months in home-based HIV/AIDS care. Her particular questions were CCGs perceptions of their work, what their work entailed, the intensity and form of care provided and the supervision received. Uys found that the CCGs were generally satisfied with their work, despite challenges which included the large economic needs of their communities, safety risks when visiting some clients, difficulty asserting themselves when working with other care network professionals, a lack of respect for their work by the formal health sector. The CCGs felt they were making a difference and the PWAs supported this notion in saying that the CCGs were very successful in enhancing the human dignity of PWAs. The study found that the most common form of care was counselling and information (94%) followed by symptom control (68%), both of which were mentioned as useful services by the PWAs and carers.</p>	<p>The article provides a useful comparison for the current study in its interviews with multiple organisations on services which included forms of care provided.</p>
<p>Viswanathan, M., Kraschnewski, J., Nishikawa, B., Morgan, L.C., Thieda, P., Honeycutt, A., Lohr, K.N., Jonas, D. (2009). <i>Outcomes of Community Health Worker Interventions. Evidence Report/Technology Assessment No. 181</i>. AHRQ Publication No. 09-E014. Rockville, MD: Agency for Healthcare Research and Quality.</p>	<p>This systematic review of CHW interventions sought to determine CHWs characteristics, CHW intervention characteristics, cost-effectiveness and outcomes along with CHW training characteristics. This is because CHW use is a key recommendation for reducing health disparities in the USA. The review included 53 studies focused on CHW intervention characteristics and outcomes, 6 on cost-effectiveness (insufficient for analysis) and 9 on CHW training (little evidence). The review found little evidence that CHW interventions improve participant knowledge relative to other approaches (from five studies), mixed evidence on CHW ability to create behaviour change or improve health. The study found a low/ moderate level of evidence on CHW ability to facilitate appropriate health care utilisation and the effectiveness varied across different health interventions. The authors concluded that CHWs can be effective in reaching underserved populations, dependent on health condition. They found insufficient and inadequate evidence in many facets of CHW work. One notable point from the discussion was, “CHWs, by virtue of their role as a bridge to the health care system, can help to disseminate widely efficacious interventions to populations that rarely benefit from health care advances.”</p>	<p>This review focused on CHW outcomes included knowledge and behaviour change and it also looked at CHW training. This provides some useful information, but it is inhibited by incomparability of included studies.</p>



UNIVERSITY OF CAPE TOWN

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26 July 2010

HREC REF: 190/2010

Ms R Zulliger
c/o Dr H Schneider
Public Health & Family Medicine

Dear Ms Zulliger

PROJECT TITLE: HEALTH INFORMATION IN THE HOME (HIH): APPROPRIATENESS AND QUALITY OF COMMUNITY CARE WORKERS' HEALTH INFORMATION PROVISION IN A RURAL SOUTH AFRICAN SUB-DISTRICT.

Thank you for responding to the issues raised by the Faculty of Health Sciences Human Research Ethics Committee.

It is a pleasure to inform you that the Ethics Committee has **formally approved** the above-mentioned study.

Approval is granted for one year till the 15th August 2011.

Please submit an annual progress report if the research continues beyond the approval period. Please submit a brief summary of findings if you complete the study within the approval period so that we can close our file.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC. REF in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSE HUMAN ETHICS

S Thomas

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

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Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

R14/49 Dr Mosa Moshabela

CLEARANCE CERTIFICATE

M090232

PROJECT

Investigate the Contributions and Attributes of Home-Based Care (HBC) in Rural South Africa

INVESTIGATORS

Dr Mosa Moshabela.

DEPARTMENT

School of Public Health

DATE CONSIDERED

09.02.27

DECISION OF THE COMMITTEE*

Approved unconditionally

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

DATE

09.03.30

CHAIRPERSON.....

(Professor P E Cleaton Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Dr M Moshabela

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.

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Social Science & Medicine provides an international and interdisciplinary forum for the dissemination of social science research on health. We publish original research articles (both empirical and theoretical), reviews, position papers and commentaries on health issues, to inform current research, policy and practice in all areas of common interest to social scientists, health practitioners, and policy makers. The journal publishes material relevant to any aspect of health from a wide range of social science disciplines (anthropology, economics, epidemiology, geography, policy, psychology, and sociology), and material relevant to the social sciences from any of the professions concerned with physical and mental health, health care, clinical practice, and health policy and organization. We encourage material which is of general interest to an international readership.

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