



**UNIVERSITY OF
KWAZULU-NATAL**

**INYUVESI
YAKWAZULU-NATALI**

MASTERS DISSERTATION

*Water, Sanitation and Hygiene in Community and Home-Based Care for People Living with
HIV/AIDS/TB in Durban, South Africa*

By

Chanelle Mulopo

STUDENT NUMBER: 209519902

SUPERVISOR: Dr Olagoke Akintola

*Submitted in partial fulfilment of the requirements of a degree of Masters in Social Science,
(Health Promotion), in the graduate Programme of Psychology, University of KwaZulu-Natal,
South Africa*

DECEMBER 2015

DECLARATION

I **Chanelle Mulopo**, hereby certify that I am the sole author of this dissertation entitled “**Water, Sanitation and Hygiene in Community and Home-Based Care for People Living with HIV/AIDS/TB in Durban, South Africa**”. This dissertation is a presentation of my original work unless otherwise indicated in the text. All referenced materials, citations and contributions of others have been duly acknowledged. The work was done under the guidance and supervision of Dr Olagoke Akintola at the University of KwaZulu-Natal. This research has not been previously submitted for any degree and is not being currently considered for any degree and/or examination at any other university.

Name: Chanelle Mulopo

Signature: _____

Date: December 2015

DEDICATION

This dissertation is dedicated to the two very special people in my life, my beautiful and loving brothers, **GLORY MULOPO** and **DANNY C. MULOPO**. You have been my inspiration, the reason for my perseverance in my studies and life. I always want to do more because of you. No words can truly capture and express the deep love that I have for you, my dearest brothers. I am truly blessed to have you in my life. This is the beginning of many greater things to come. You are deeply loved and appreciated.

I also take this opportunity to pray that the souls of the following beautiful people rest in peace: Papa Charles Kabalambi, Ma Ndekenya and Grandpa Mutombo Kabwe. You will always have a very special place in my heart.

I LOVE YOU

ACKNOWLEDGEMENTS

First and foremost I thank God for being with me throughout this project, It is due to His unfailing love, strength, courage and wisdom that I was able to start and finish this project. May all the glory and honor be unto God:

“For I am God’s own workmanship, created in Christ Jesus to do good works, which God prepared in advance for me to do” (Ephesians 2:10).

I would also like to acknowledge the School of Applied Human Sciences at the University of KwaZulu-Natal for funding my tuition through my supervisor, Dr Olagoke Akintola. To my supervisor, thank you for the support and guidance that you offered me throughout the research process, for being a great mentor, a source of encouragement and for continuously imparting your knowledge, wisdom and experience in this field of study.

I thank my Daddy, Mr Ambrose Maweja Mulopo, for being such a loving and supportive father. I wouldn’t be where I am today if it wasn’t for your support. Your prayers have always kept me. Thank you for all your support and for believing in my dreams. My dearest mama, I love you and thank you. I would also like to thank my new family, my step mom and brothers.

I also thank my spiritual family and friends. Mrs Carol Bartman, you have been like a mother to me and have shown me so much love and support. My dear friends, Nolwazi K. Nzama, Mlodolozzi Myeza, Patrick Nymaruze, Rudzani Mtibi, Tintswalo Ngulele, Mbali Mkhwanazi, Lydia H. Mudenda and Olatunde Durowoju, thank you for your support and encouragement. I would also like to thank the research team for all your hard work and commitment; you made this journey worthwhile: Nolwazi K. Nzama, Mlodolozzi Myeza, Thobeka N. Mkhize, and Asiphe O. Mashinini, your input is highly appreciated.

Finally, my heartfelt gratitude goes to the Community Health Workers who welcomed me in their communities and line of work and shared their life experiences, enabling me to collect the information needed. This research would not have been possible without you. I honor you for the women you are and the work you do. THANK YOU!

ABSTRACT

Water, Sanitation and Hygiene in Community and Home-Based Care for people living with HIV/AIDS/TB in Durban, South Africa

The majority of HIV/AIDS patients in South Africa receive health care services at home. However, few studies have examined water; sanitation and hygiene (WASH) in home and community-based care. The main objective of this study was to explore community health workers' (CHWs) perceptions of WASH in home-based care and the implications for people living with HIV/AIDS/TB, their family members and the health workers themselves. The participants in this qualitative study were drawn from four community home-based care organizations that provide care to HIV/AIDS/TB clients. These organizations are located in four marginalized communities in Durban. Data was collected using participant observation of care-giving activities; semi-structured interviews with five home-based care project managers from the organizations and five focus group discussions with a total of 49 CHWs.

Some AIDS patients are incontinent. It is typical for CHWs to find patients in closed areas with bedding soiled by urine and feces. It was found that CHWs had limited access to protective materials such as gloves and aprons and therefore tended to avoid carrying out activities that could help maintain proper hygiene in the home for fear of infection. Furthermore, limited access to water and an unreliable water supply meant that CHWs had to fetch water from immediate neighbors or surrounding areas and this limited the time spent with their patients. The unavailability of water had ramifications for the number of times patients could bath. Insufficient water also presented a challenge to CHWs and families in maintaining proper sanitation.

There is a great need for adequate water, proper sanitation and hygiene in community-based care. Inadequate access to water influences sanitation and hygiene, and this affects the work of CHWs. The government needs to respond promptly to the water and sanitation needs of marginalized communities with limited resources. The study's findings have implications for policy on WASH and community-based care in low-income communities.

Keywords: Water, Sanitation and Hygiene (WASH), HIV/AIDS/TB, home and community-based care, community health workers, care-givers, South Africa.

TABLE OF CONTENTS

DECLARATION	1
DEDICATION	2
ACKNOWLEDGEMENTS.....	3
ABSTRACT.....	4
LIST OF FIGURES AND TABLES.....	8
CHAPTER ONE	9
INTRODUCTION	9
1.1 Introduction and background to the study.....	9
1.2 Problem statement.....	11
1.3 Aim of the study and research questions.....	11
1.3.1 Key objectives of the study	11
1.3.2 Research Questions.....	12
1.4 Structure of the dissertation.....	12
CHAPTER TWO	14
LITERATURE REVIEW	14
2.1 Introduction.....	14
2.2 Primary Health Care: An approach to Health for All?.....	14
2.2.1 Dracunculiasis: A disease perpetuated by poor quality water sources.....	19
2.2.2 Action through social determinants of health to achieve health for all	21
2.3 Water, sanitation, hygiene and health	23
2.3.1 Water, sanitation and hygiene in South Africa.....	27
2.4 Home and community-based care.....	28
2.4.1 Challenges faced by Home and Community-Based Care Organizations.....	29
2.4.2 Water, Sanitation and Hygiene in Home and Community-Based Care	30
2.5 Theoretical framework	32
2.5.1 The ecological systems theory.....	32

2.5.2 Levels of ecological systems theory as applied to the present study.....	35
2.5.3 The micro-system	36
2.5.4 The meso-system	36
2.5.5 The exo-system.....	37
CHAPTER THREE	38
RESEARCH METHODOLOGY	38
3.1 Introduction	38
3.2 Research context and setting.....	38
3.3 Design of the study.....	39
3.4 Study sample	40
3.4.1 Selection of study Participants	41
3.4.2 Study Participants	42
3.5 Data collection procedure.....	43
3.5.1 Data collection methods	43
3.5.2 Focus group discussions with Community Health Workers	43
3.5.3 In-depth interviews with home-based care managers.....	44
3.5.4 Participant observation	45
3.5.5 Data collection instrument.....	45
3.6 Method of analysis	46
3.7 Ethical Considerations.....	47
3.8 Trustworthiness of the study	47
CHAPTER FOUR.....	49
Experiences of WASH by Community Health Workers in Community-based Care	49
4.1 Introduction	49
4.2 Access to water.....	51
4.2.1 Availability of water.....	51

4.2.2 Reliability of water	54
4.2.3 Hygiene conditions of communal taps	55
4.3 Sanitation and hygiene	59
4.3.1 Conditions of homes and toilets	59
4.3.2 Inadequate water to clean homes and toilets	63
4.3.3 Waste Management	65
4.3.4 Hygiene practice in home-based care	67
CHAPTER FIVE	73
DISCUSSION OF FINDINGS	73
5.1 Access to water in community and home-based care	73
5.2 Conditions of homes and toilets in community and home-based care	76
5.3 Waste management and hygiene practice in community and home-based care	78
5.4 Conclusion, recommendations and the limitations of the study.....	80
5.4.1 Conclusion	80
5.4.2 Recommendations for future research.....	82
5.4.3 Limitations of the study	82
5.5 Conclusion.....	83
REFERENCES	84
Appendix A: ETHICAL CLEARANCE LETTER.....	97
Appendix B: INFORMED CONSENT FORM	98
Appendix C: INTERVIEW GUIDE FOR CHWs AND HBC MANAGERS/FOUNDERS	101

LIST OF FIGURES AND TABLES

Figure 1.1: Global estimates of water and sanitation by region.....	24
Figure 1.2: Population with inadequate water by region.....	25
Figure 1.3: Population with unimproved sanitation by region.....	25
Figure 2.1: Bronfenbrenner’s ecological systems theory.....	33
Figure 2.2: Bronfenbrenner’s ecological system theory as applied to the study.....	35
Table 3.1: Summary description of participants and HBC organisations.....	41
Figure 3.1: Summary of themes and sub-themes.....	50
Figure 4.1: Photograph of a communal standpipe.....	51
Figure 4.2: Photograph of a local municipal water tanker.....	55
Figure 4.3: Photograph capturing the conditions surrounding communal water sources.....	56
Figure 4.4: Photograph of water storage in some households.....	57
Figure 4.5: Photograph of different types of houses in informal settlement.....	59
Figure 4.6: Photograph of pit-latrines.....	61
Figure 4.7: Photograph of waste disposed on the roadside.....	62
Figure 4.8: Photograph of garbage on the roadside.....	67
Figure 4.9: Photograph of a CHW attending to a patient without gloves.....	69
Figure 4.10: Summary of the relationship between water, sanitation and hygiene and CHWs....	72

CHAPTER ONE

INTRODUCTION

1.1 Introduction and background to the study

Approximately three billion people in the developing world suffer from a plethora of infectious diseases (Walsh & Warren, 1979). The World Health Organization (WHO) estimates that 80% of all sicknesses and disease in the world is attributable to inadequate water and sanitation. This is the result of drinking contaminated water, water acting as a breeding ground for carriers of diseases or diseases caused by not washing or a lack of water (Agarwal, Kimondo, Moreno & Tinker, 1981). The health consequences of poor water, sanitation and hygiene (WASH) are enormous (World Health Organization [WHO] & United Nations Children's Emergency Fund [UNICEF], 2015).

Universal access to primary health care (PHC) is acknowledged as the best solution to address the problem of disability and death resulting from inadequate water and sanitation. At the United Nations (UN) Water Conference in 1977, 1981-1990 was declared the international drinking water supply and sanitation decade (IDWSSD) to respond to high levels of water-related deaths (Falkenmark, 1982). The IDWSSD was linked to PHC initiatives. The objective was to provide all people with safe water and basic sanitation facilities by 1990 (O'Rourke, 1992). Furthermore, the WHO conference held at Alma-Ata in 1978 adopted a declaration (commonly referred to as the Alma-Ata Declaration) that aimed to deliver health to all using a PHC approach.

Equity was one of the main issues highlighted in this declaration. It noted that the inequities that exist between and within countries were politically, economically and socially unacceptable (Sanders, 2003) and acknowledged that the main determinants of health lay outside the health sector. The declaration advocated for equity in accessing social determinants of health such as housing, education, employment, water and sanitation in order to improve health (Baum & Sanders, 1995).

However, the comprehensive approach to primary health care (CPHC) was short-lived as it was criticized for being too broad and idealistic. A year later, Drs Walsh and Warren came up with what is known as selective primary health care (SPHC) (Walsh & Warren, 1979). They believed that a selective attack on the most severe public health problems would improve health and medical care in developing countries. Selective primary health care focused on five to eight diseases and

did not include water and sanitation activities (Unger & Killingsworth, 1986). The focus was the prevention or treatment of those diseases that were responsible for the highest mortality in less developed areas of the world (Walsh & Warren, 1979). Thus, it can be argued that SPHV elevated treatment above prevention, because the provision of water and sanitation is an effective measure to prevent many diseases.

Moreover, SPHC neglected some of the key factors of PHC such as equity, intersectorality and community participation and emphasized cost effective, vertical programs. After several years of investment in such programs, preventable diseases remained a major challenge for developing countries. Therefore, there was a need to formulate alternative global strategies to improve health. An international agreement was signed at the WHO first international conference on health promotion in Ottawa, Canada in 1986. Referred to as the Ottawa Charter, it adopted strategies to improve health that go beyond the health sector. The charter acknowledged that the major factors that shape health are embedded in society rather than the health sector (Mann, 1996).

The Ottawa Charter, which was inspired by the Alma-Ata Declaration, reinstated the importance of equity in health. Equity and the social determinants of health were further highlighted in a report released in August 2008 by the Commission on Social Determinants of Health. The report noted that health disparities between and within countries were the result of the circumstances in which people grow, live, work and age and that water and sanitation were major determinants of health (Marmot, Friel, Bell, Houweling & Taylor, 2008; Commission on Social Determinants of Health [CSDH], 2008).

It is crucial that people living with HIV/AIDS (PLWHA) and receiving community and home-based care have access to safe water because they are more susceptible to water-borne diseases due to their compromised immune system (United States Agency for International Development [USAID], 2004). It is estimated that diarrhea affects 90% of HIV/AIDS-infected people and results in significant morbidity and mortality (Makaudze, du Preez & Potgieter, 2012). Revisiting CPHC and its major components such as the focus on equity and the social determinants of health could mitigate some of the challenges confronting home-based care (HBC).

1.2 Problem statement

Few studies have explored and/or assessed water, sanitation and hygiene together in community and home-based care. Ngwenya and Kgathi's (2006) study in Botswana found that care giving households had limited access to water; moreover, caregivers reported that the insufficient water supply affected their day-to-day activities. Potgieter, Koekemoer and Jagals (2007) concluded that problems associated with WASH were hampering the effective treatment of PLWHA in HBC. One of the key findings of Potgieter and du Preez's (2012) study is that PLWHA and households affected by HIV/AIDS have a substantially greater need for safe WASH. Akintola and Hangulu's (2014) study conducted in Durban revealed poor sanitation and hygiene practices in HBC which could increase the risk of TB and HIV transmission. These findings were similar to those of Blinkhoff et al. (2001) that found that volunteering for home care was associated with the risk of HIV/AIDS and TB infection. Thus, the current study examined caregivers' perspectives on WASH in HBC and the implications for PLWHA, their family members and CHWs. The study's findings have implications for health care policy. Policy-makers should ensure that the issues relating to WASH are addressed at community level. Moreover, the findings could inform policy on WASH in community-based care and on water and sanitation delivery in low-income communities.

1.3 Aim of the study and research questions

The aim of this study was to understand the importance of WASH in community and home-based care for PLWHA in South Africa and the implications of WASH for the general well-being of individuals living with HIV/AIDS, their family members and CHWs. The results could inform relevant government departments on the status of WASH in HBC so that the necessary steps can be taken to address the situation. The findings could also inform policy around WASH in HBC.

1.3.1 Key objectives of the study

- To explore WASH in community and home-based care.
- To understand the challenges faced by CHWs with regard to WASH in community and home-based care and how they cope with these challenges.
- To describe the implications of WASH for the general well-being of PLWHA, their family members and CHWs.

1.3.2 Research Questions

- What is the current situation in relation to WASH in community and home-based care?
- What challenges do CHWs face with regard to WASH in community and home-based care?
How do they cope with these challenges?
- How does WASH affect the general well-being of PLWHA, their family members and CHWs?

1.4 Structure of the dissertation

This dissertation consists of five chapters.

Chapter One: Chapter one presents an overview of the study. It provides background information that situates the study in a specific context. The importance of the study is highlighted by means of a problem statement. Finally, the aim, key objectives and research questions are outlined.

Chapter Two: This chapter begins by reviewing the relevant literature on WASH. The literature review is presented chronologically in terms of major decisions on PHC as an interim strategy for health for all. The literature on WASH as key factors in achieving health and that on WASH in HBC is also reviewed. Finally, the chapter applies the ecological systems theory as the theoretical framework that guided this study.

Chapter Three: This chapter describes the steps followed to collect data for the study. A total of 54 people participated in the study, made up of 49 CHWs and five HBC project managers/founders. Five focus group discussions were conducted with CHWs and five in-depth interviews with HBC project managers. Semi-structured interviews and focus group discussions were used to gather information from the participants. The data were analyzed using thematic analysis as advocated by Braun and Clark (2006).

Chapter Four: This chapter presents the study's findings using narratives and direct quotations from the participants, supported by photographs.

Chapter Five: The final chapter discusses the findings presented in Chapter 4. The chapter ends with a conclusion as well as well as recommendations for future research. The study's limitations are also covered in this chapter.

The final sections contain the references and documents used in the study.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

While WASH are essential to the well-being of all individuals, it is even more important for PLWHA to have access to clean water and proper sanitation. Given the fact that many PLWHA in South Africa receive care at home, it is important to investigate WASH and HBC. Previous research on community-based care has mainly focused on areas such as the burden of care, volunteer caregivers' motivation, etc.; few studies have explored WASH in community based-care.

This literature review addresses three broad areas related to WASH. The first section discusses water as an essential element of PHC as stipulated in the Alma-Ata Declaration of 1978. The second section reviews the body of literature on water, sanitation and hygiene at the global level and in South Africa. Finally, section three focuses on research on issues relating to WASH in community-based care.

2.2 Primary Health Care: An approach to Health for All?

In 1978 an international conference on primary health care was held in Alma-Ata, the then capital of Kazakhstan in the former Union of Soviet Socialist Republics (USSR) now known as Almaty. This conference was a landmark event for PHC. It adopted the slogan “Health for All by the year 2000” (Cueto, 2004) and, importantly, recognized that the main determinants of health lay outside the health sector. These include food, housing, employment and **water and sanitation** (Baum and Sanders, 1995). Therefore in order to improve health for all, it is imperative to redress the inequities within and between countries with regard to access to the social determinants of health.

A target was set that, by the year 2000, all individuals would be able to access health in their respective countries. This would enable them to achieve the highest possible standard of health (Schaay & Sanders, 2008). The declaration was based on three key ideas: “appropriate technology, opposition to medical elitism and the concept of health as a tool for socioeconomic development” (Cueto, 2004, p. 4). It aimed to reform and transform health policies and plans in developing nations (Magnussen, Ehiri, & Jolly, 2004). Furthermore, during the conference, the definition of

health was reaffirmed as “a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity” (WHO, 1946 p. 100). Health was declared a fundamental human right and attainment of the highest possible level of health became a significant global social goal (Magnussen et al., 2004).

The goal of health for all by the year 2000 was to be achieved through a comprehensive approach referred to as PHC. Primary health care highlights equity in accessing basic health care services. It advocates for prevention and health promotion and for health to be promoted through targeting and taking action outside the health sector (Baum & Sanders, 1995). Prior to the implementation of PHC, diseases caused by poor water and sanitation services resulted in a high mortality rate across the globe. Indeed, one in four patients admitted to hospital died from water-related diseases (Falkenmark, 1982). Consequently, the UN Water Conference held in 1977 declared 1981-1990 the international drinking water supply and sanitation decade (IDWSSD) that was linked to the PHC initiative. Its objective was to “provide all people with water of **safe quality in adequate quantity and basic sanitation facilities** by 1990 giving priority if possible to the poor and less privileged” (United Nations Procurement Division [UNDP], 1980).

Primary health care had strong socio-political implications as it sought to respond more equitably, appropriately and effectively to basic health needs while paying particular attention to the underlying social, economic, and political causes of poor health (Sanders, 2003). Moreover, the underlying aim of the IDWSSD was to improve people’s health through improved water supply and sanitation (O’Rourke, 1992). Unfortunately, the decade did not fully achieve its goal. Due to the increase in population and urbanization, globally, more people did not have adequate water and sanitation by the end of the decade than at its inception (Warner, 1990). Furthermore, the initiative failed due to the fact that the employees assigned to implement the IDWSSD were also working on the PHC initiative. The latter received more attention than the former (O’Rourke, 1992). However, despite the structural challenges confronting the IDWSSD, it achieved significant expansion in water coverage.

It was suggested at the Alma-Ata conference that PHC should include eight basic elements which, at the very least, would contribute to health for all by the year 2000. The components included the promotion of food supply and nutrition, maternal and child health care, including family planning,

immunization, prevention and control of local diseases and treatment, provision of drugs and health education and the provision of safe drinking water and sanitation (WHO & UNICEF, 1978).

The Alma-Ata Declaration inspired the Ottawa Charter of 1986, an international agreement signed at the first WHO international conference on health promotion held in Ottawa, Canada. The charter adopted the WHO definition of health and moved from viewing health as a dichotomy disease model to one that is a product of life (Potvin & Jones, 2011). The Ottawa Charter outlined strategies to improvement health that went beyond the health sector, as it acknowledged that the major factors that shape health have their origins in society rather than in the health sector (Mann, 1996).

Moreover, the **provision of safe drinking water and sanitation** services was regarded as an essential component of PHC that contributes to the vital global target of health for all (WHO and UNICEF, 1978). This new approach directly linked health to development. Comprehensive PHC emphasized disease prevention and health promotion, community participation, self-reliance and intersectoral collaboration (Tarimo & Webster, 1994). As such, it included all eight components noted above.

The intersectoral or multi-sectorial approach advocates that health issues should be addressed by different sectors. The Ottawa conference established the relationship between health and other institutions. This meant that public and private institutions working on health-related issues such as health education, adequate housing, **safe water and basic sanitation** should come together to tackle health problems (Cueto, 2004; Magnussen et al., 2004; Sanders, 2003, Schaay & Sanders, 2008). In other words, water and sanitation is a determinant of health. Consequently, the provision of safe drinking water and sanitation services improves people's health. The provision of water and sanitation was noted as a key aspect in attaining health for all by the year 2000. This is illustrated as follows:

....The attainment by all peoples of the world by the year 2000 of a level of health that will permit them to lead a socially and economically productive life. Primary Health Care is the key to attaining this target..... [and] includes at least: education concerning prevailing health problems and the methods of preventing and controlling them; promotion of food

supply and proper nutrition, maternal and child health care, including family planning; immunization against the major infectious diseases, prevention and control of locally endemic disease; appropriate treatment for common diseases and injuries, provision of essential drugs and **an adequate supply of safe water and basic sanitation**. (WHO & UNICEF, 1978, p. 34)

However, it can be argued that CPHC never materialized and its transformative potential remained largely untapped. Primary health care was criticized for being too expensive, broad and idealistic and having an unrealistic timetable (Walsh & Warren, 1979). Consequently, a year later in 1979 at a joint Ford and Rockefeller Foundation symposium on health services in Bellagio, Italy, Drs Walsh and Warren revised the scope and definition of PHC (Yacoob, Brieger & Watts, 1989). A new perspective was introduced known as SPHC which became an “interim” strategy to begin the process of primary health care implementation (Walsh & Warren, 1980). This movement gained momentum and rejected the key factors of PHC – equity, intersectorality and community participation – in favor of cost-effective vertical programs. Vertical programs are directed by a team of specialized health workers. The team supervises and either fully or to a large extent executes the program; this is also referred to as the top-down approach (Mills, 1983).

Selective primary health care neglected some aspects of PHC that were included in the declaration of 1978. These include the focus on equity, community participation (a bottom-up approach), prevention and control of diseases, and the provision of safe water and basic sanitation (Schaay & Sanders, 2008; Yacoob et al., 1989). Instead, SPHC emphasized low-cost technical interventions that were measurable and clear targets (Cueto, 2004). This narrow focus on specific conditions was designed to improve health statistics (Magnussen et al., 2004).

The new perspective of SPHC led to a focus on four types of interventions commonly referred to as GOBI. The first focused on monitoring the growth of infants, while the second highlighted oral rehydration and the third promoted breastfeeding of infants. Finally, the fourth intervention focused on immunization and supported vaccination, especially in early childhood. These can be characterized as child survival interventions. Family planning, female education, and food supplementation (FFF) were later added to the four vertical programs (Magnussen et al., 2004).

Selective primary health care ignored Alma-Ata's focus on social equity, which ensures that some citizens are not denied the benefits enjoyed by others. It also neglected the issue of provision of clean water and sanitation even though a lack of clean water causes many deaths in developing nations (Yacoob et al., 1989).

According to Walsh and Warren (1980), the estimated cost of improved water supply and sanitation projects was too high. However, Okun (1987) argued that the price of low-cost water technologies ranged from \$US 14 to 38 per capita and basic sanitation cost as low as \$US 3 to 5.50 with a life span of 20 years and more. Moreover, these costs compared favorably with the cost of child survival interventions, with the lowest cost of fully immunizing a child standing at \$US 11.75 in 1989 (Claquin, 1989). Lieberson, Miller, Eckerson and Keller (1987) reported that the cost of the use of ORT for the treatment of diarrhea in Gambia was \$US 1.56 per child per annum. Thus, it can be argued that SPHC focused on the treatment of symptoms rather than the problem and did not tackle the root cause of many deaths in developing countries (Yacoob et al., 1989). Furthermore, it can be argued that the provision of a clean, convenient water supply and basic sanitation should be an important aspect of PHC since many deaths in developing nations are a result of unclean water and a lack of or poor sanitation.

Drs Walsh and Warren neglected an important aspect of CPHC which is community participation. According to sectorial experience, water is universally the first and most immediate need that communities recognize (Okun, 1987). Improved provision of water through the installation of piped water systems could be expensive. However, an array of low-cost, rural technologies is available, such as hand-pumps, hand-dug wells; water jars primarily for drinking water and the use of filters (Brieger, Otusanya, Adeniyi, Tijani & Banjoko, 1997). Moreover, such technologies can complement existing water sources for activities such as laundry, washing floors, watering the garden etc. where the purity of the water is of little or no consequence (Yacoob et al., 1989). Thus, CPHC should incorporate appropriate technology.

Gunnerson, Julius and Kalbermatten (1978) defined appropriate technology as "that process or technique which provides a socially or environmentally acceptable level of service or quality of product at the least social cost" (p. 32). In other words the product must be cheaper, installation must be simple, and it should be easy to operate and maintain using the knowledge available in the community (WHO, 1981). However, it is argued that such technology has not been appropriately

applied in developing countries. For example, the water and sanitation decade was deemed the decade of hand pumps. According to Walters (1989), 80% of these pumps are out of order at any one time. While local users have experienced difficulty in operating and maintaining hand pumps, Brieger et al. (1997) argue that they can be easily fixed.

A convenient water supply is crucial for the development of a community. Water, sanitation and hygiene interventions in poor communities with poor quality water and inadequate sanitation have been shown to reduce the risk of water-borne and water-related diseases such as ascariasis, dracunculiasis, hookworm infection, schistosomiasis and trachoma (Esrey, Potash, Roberts & Schiff, 1991; Strunz et al., 2014). Thus, the provision of low cost WASH technologies at different levels such as the individual, household and the community is crucial in preventing such diseases in poorly resourced regions (Dreibelbis et al., 2013). Interventions such as providing hand washing soap, an integrated water supply and sanitation and household and village level treatment, water storage and hygiene education have successfully reduced the occurrence of water-borne and water-related diseases (Aiello, Coulborn, Perez & Larson, 2008; Curtis & Cairncross, 2003; Nanan, White, Azam, Afsar & Hozhabri, 2003). A study conducted in Kenya found that the risk of diarrhea attributed to WASH can be curbed by improving excreta disposal, hygiene practices and water quality (Bisung, Elliot, Abudho, Karanja & Schuster-Wallace, 2015).

When water is not easily accessible, women who are traditionally responsible for fetching water for the household, spend a disproportionate amount of time doing so. When water can be easily accessed, women have the time to discuss and solve prominent problems in the community and to engage in economic development (Bisung et al., 2015; Brieger et al., 1997; Falkenmark, 1982). Conversely, when women spend several hours fetching water, they are less able to contribute to development in their community (Akintola, 2008; 2010; Brieger et al., 1997). Moreover, they may also not have sufficient time and energy to adopt the child survival measures propagated by SPHC such as breastfeeding, taking the child to the nearest clinic for immunization or ORT, etc. (Yacoob et al., 1989). Hence, the provision of water is crucial to the development of communities.

2.2.1 Dracunculiasis: A disease perpetuated by poor quality water sources

Dracunculiasis or guinea worm disease is an example of a disease caused by poor quality water sources. There is a high prevalence of this disease in sub-Saharan African countries (Watts, 1986). Women infected by the guinea worm become bedridden and incapable of taking care of

themselves. They are unable to perform essential activities such as bathing, accessing a toilet and maintaining hygiene within their homes. As a result of the physical effort required to perform such activities, some women find it easier to simply do away with them (Yacoob et al., 1989). This impacts hygiene in their home as well as their personal well-being.

Guinea worm disease can easily be controlled by the provision of low-cost technologies such as a hand-pump that is conveniently sited and is exclusively for drinking water (Bourne, 1986). This raises questions as to why there continues to be a high prevalence of this disease in developing countries. As noted earlier, guinea worm disease has debilitating effects. For example a study conducted in Nigeria among women infected with guinea worm found that the majority were unable to perform all or some of their duties (Yacoob et al., 1989). The disease has come to be closely associated with poor, marginalized, rural inhabitants in developing countries who are excluded from national development programs such as water supply (Watts, 1987). The provision of a clean, safe and reliable water supply could result in its complete eradication (Brieger et al., 1997).

The debate on the eradication of guinea worm mirrored that on CPHC vs. SPHC as it was believed that water supply interventions were the most expensive approach (Hopkins, 1987). Hence there was a shift from a comprehensive approach to eradicate the disease by providing a safe water supply to targeted short-term interventions such as the use of insecticides to kill the immediate host in ponds and the use of cloth filters to remove the Cyclops (Brieger et al., 1997). It can be argued that filters, that are guinea worm specific, would not be as effective as improving the water supply since filters are not able to eradicate other organisms found in water sources containing Cyclops such as *Giardia lamblia*, *Entamoeba histolytica* and hookworm (Ilegbodu, Christensen, Wise, Ilegbodu & Kale, 1987).

Nonetheless, guinea worm eradication programs mimicked those of SPHC campaigns such as the smallpox campaign where the focus was surveillance to document and promote the achievement of zero cases (Henderson, 1987). The broader goal of a clean water supply was pushed aside for the sake of expediency (Brieger et al., 1997). The failure to provide safe water to communities has had far reaching ramifications and has resulted in continued prevalence of guinea worm disease among marginalized communities.

After several years of investment in vertical programs endorsed by the notion of SPHC, preventable diseases remained a major challenge to developing countries. The selective model did not respond adequately to the interrelationship between health and social development. Consequently a rethink of global health policy was urgently needed. The key concept of PHC acknowledged that many health problems arise outside the health sector and that equity within and between countries is the key to improving health for all. The Commission on Social Determinants of Health (CSDH) sought to reintroduce the notion of equity in improving health for all. Its report was released in August 2008. The commission adopted a comprehensive approach to dealing with global health inequities by examining the social determinants of health (CSDH, 2008).

2.2.2 Action through social determinants of health to achieve health for all

Both the Alma-Ata Declaration and the Ottawa Charter emphasized that social factors that exist outside the health sector are major determinants of health (Baum and Sanders, 1995; Mann, 1996). The health disparities between the rich and poor are a result of inequities in access to the social determinants of health. These inequities arise from the circumstances in which people grow, live, work and age. Health inequities exist between countries and within countries. Furthermore, the health gap between developed and developing countries and within a country follows a social gradient; the lower one's socioeconomic status, the worse one's health (Marmot et al., 2008). The CSDH was established by the WHO in 2005 to investigate what could be done to promote global health equity and to launch a global movement to achieve health equity (CSDH, 2008).

The central goal of the commission was to strengthen health equity worldwide and within countries by moving beyond concentration on the immediate causes of disease to focus on the underlying causes (Marmot, 2007). The structural determinants of health (such as unequal distribution of services) and conditions of daily life (people's homes and communities) make up the social determinants of health and cause much of the health inequity between and within countries. Consequently, the commission took a holistic view of the social determinants of health to tackle global health inequities (CSDH, 2008).

The CSDH aimed to close the health gap within the lifespan of one generation. It set three major objectives: to improve the conditions of daily life (the circumstances in which people are born, grow, live, work and age); to tackle the inequitable distribution of power, money and resources (the structural drivers of the conditions of daily life) globally, nationally and locally; and finally,

to measure the problem, evaluate action, expand the knowledge base and develop a workforce that is trained in the social determinants of health, and raise public awareness of such determinants (Marmot et al., 2008).

Where people live is a social determinant of health; therefore, it is important that people live in healthy places in order for them to flourish. According to the Worldwatch Institute (2007), as a result of rural-urban migration, almost one billion people live in slums. In developing countries, half of all urban dwellers live in slums, and in the poorest countries the number rises to four out of five (UN-HABITAT, 2003). For the first time, there were more people living in urban areas than rural settings in 2007. These regions are a breeding ground for infectious diseases. Many households in informal settlements do not have access to adequate shelter, and suffer a lack of safe water and adequate sanitation (Misselhorn, 2010). According to Bijerregaard, Berner and Oyvind (2008), health disparities between the indigenous and non-aboriginal population in the Arctic region were the result of diseases associated with inadequate levels of sanitation and hygiene, poor shelter and an inadequate water supply. Access to good quality housing and shelter and the services associated with it such as **clean water and sanitation** are basic needs for healthy living (United Nations Educational, Scientific and Cultural Organization [UNESCO], 2006; Shaw, 2004). The CSDH recommended that urban governance and planning should promote health and health equity by improving slums including the **provision of water and sanitation** regardless of people's ability to pay for these services (CSDH, 2008).

Tibaijuka (2004) notes that slum dwellers in Nairobi and Dar-es-Salaam do not have access to water. They buy water from private vendors and pay as much as five to seven times more for a liter of water than a regular North American resident. According to the WHO/UNICEF, shared sanitation facilities are regarded as inadequate. Studies conducted in Rwanda and Uganda show that households in informal settlements share sanitation facilities due to overcrowding; there is insufficient space for every household to build their own toilet. In Uganda, 78% of households shared latrines with an average of six other households (Gunther et al., 2012; Tsinda et al., 2013). In 2010, at least 10% of South Africa's population (at that time 44 million) lived in urban informal settlements that are characterized by poor living conditions and inadequate water and sanitation services (Misselhorn, 2010).

The CSDH also recommended that equity in access to water should be a central tenet of water policy. A practical example of inequity in access to water is that of Johannesburg and Durban, South Africa where many households cannot afford an adequate water supply (Nnadozie, 2013). As noted earlier, increased access to water and sanitation empowers women and improves their health (Ivens, 2008).

2.3 Water, sanitation, hygiene and health

The literature notes that the provision of safe water and basic sanitation has positive health impacts (Montgomery & Elimelech, 2007; Daley, Castleden, Jamieson, Furgal & Ell, 2015). Moreover, the provision of safe drinking water and sanitation meets basic human needs and is a human right (O'Rourke, 1992). A lack of access to safe water and sanitation results in millions of preventable deaths among vulnerable populations (Pruss, Kay, Fewtrell & Bartman, 2002).

WHO/UNICEF (2015) progress on sanitation and drinking water report shows that there has been major achievements, with the target of meeting safe drinking water (Figure 1.1). In fact the target was met in 2010, well ahead of the 2015 deadline. However, further analysis of the report shows that even though five developing regions met the drinking water goal, sub-Saharan Africa is among the regions that did not meet the goal (Figure 1.1). Countries in which less than 50% of the population uses improved drinking water sources are all located in sub-Saharan Africa and Oceania. Therefore one can deduce that though the report shows major improvements with regards to achieving the water target, sub-Saharan Africa still faces a major challenge with regards to access to improved drinking water. Additionally the 2015 report shows that sanitation still remains a major problem with 2.4 billion people who lack improved facilities. Moreover there seem to be great disparities between the urban and rural population with regards to sanitation. Seven out of ten people without improved sanitation facilities and nine out of ten people still practicing open defecation live in rural areas. According to Gleick (2002), if no action is taken to address water and sanitation issues, diseases related to a lack of water will claim as many as 135 million lives by 2020.

The figure below shows the proportion of the 2015 population that gained access to water and sanitation since 1990 in percentage (Adopted from the WHO and UNICEF 2015).

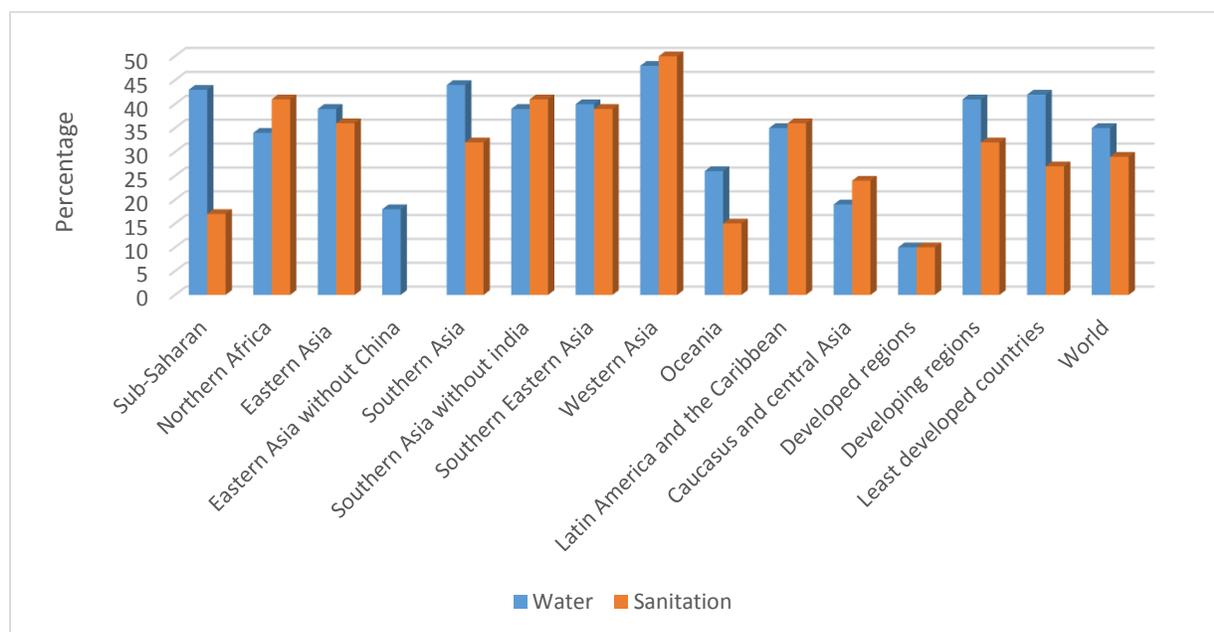


Figure 1.1 global estimates of water and sanitation by region

The global trends in drinking water show that 663 million people still lack improved water sources in the year 2015. The drinking water target was met in the year 2010 well ahead of the deadline which was 2015. According to the WHO/UNICEF 2006 report 1.1 billion people did not have access to a safe water supply, 30% of whom live in sub-Saharan Africa by the year 2006 (Figure 1.2). Moreover, 2.6 billion people, 40% of the world's population, did not have access to adequate sanitation (Figure 1.3) by the year 2006, this figure has only dropped to 2.4 billion people in 2015, falling to meet the MDG goal of halving the proportion of the population without adequate sanitation. India is home to 60% of the global population that practices open defecation (WHO & UNICEF, 2014). In 2004, more than two billion people living in rural settings did not have access to basic sanitation (WHO & UNICEF, 2006). Moreover, it was estimated that 1.7 billion rural dwellers would remain without such facilities by 2015. In contrast, in the US and Central Europe, access to water and sanitation services is virtually universal (Mara, 2003).

The figures below paint a global picture of water and sanitation (adopted from WHO and UNICEF, 2006).

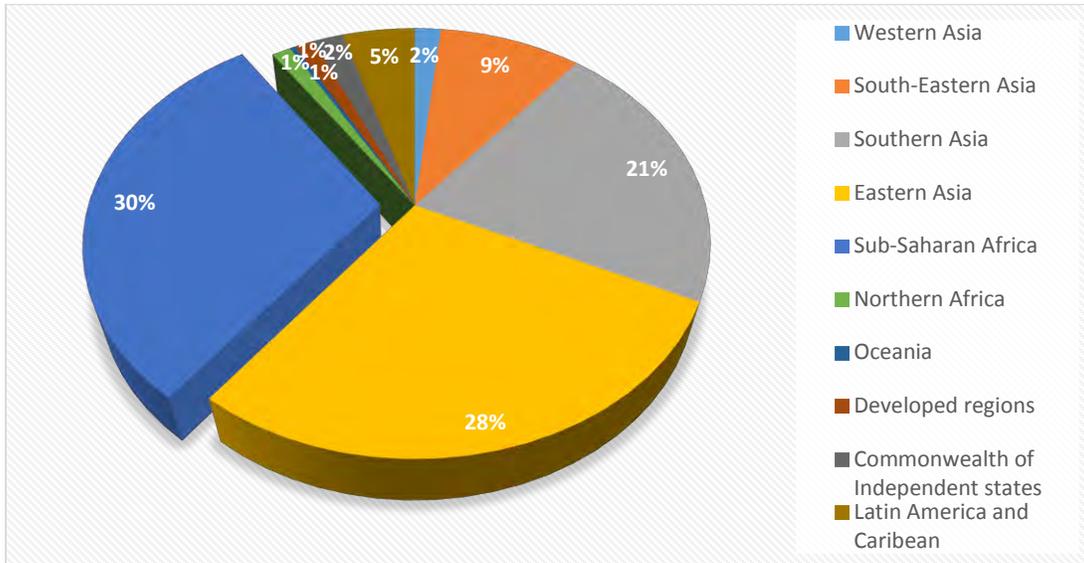


Figure: 1.2 Population with inadequate water by region

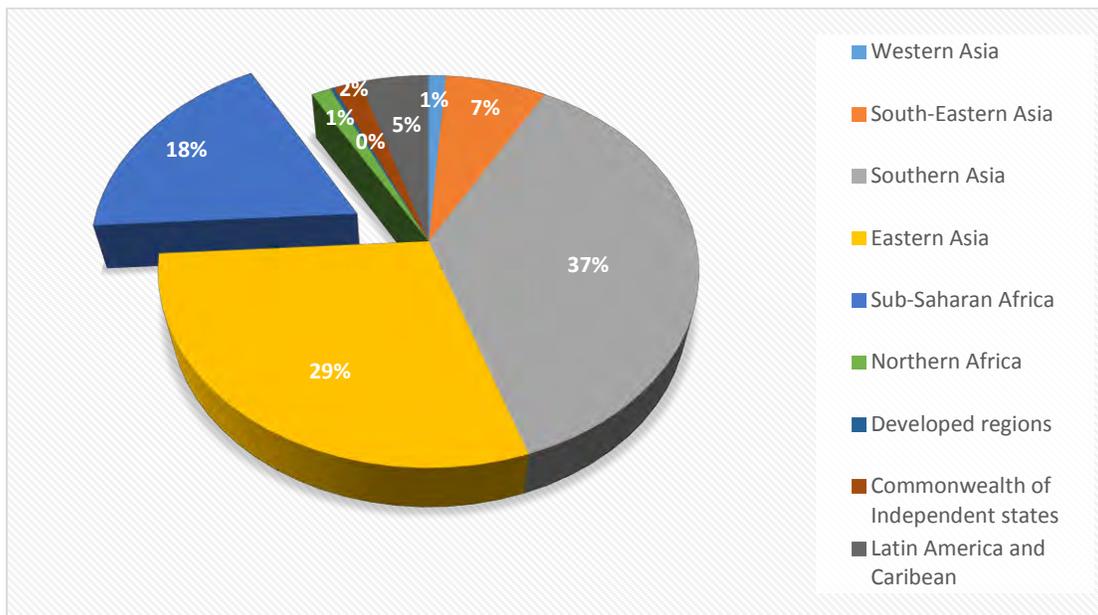


Figure 1.3 Population with unimproved sanitation by region

The figures show that water and sanitation supply are inadequate in sub-Saharan Africa. Diarrhea-related deaths are higher in this region than in any other region (WHO & UNICEF, 2006). Daley et al. (2015) found that improved water and wastewater management practices in conjunction with improvements in living conditions resulted in fundamental health improvements such as increased life expectancy and a decline in child mortality among Arctic communities. Considering that these are marginalized regions like most sub-Saharan African countries, it can be argued that similar improvements in sub-Saharan Africa would yield similar results.

Daley et al. (2015) also found that disparities in health between the indigenous Arctic population and non-aboriginal Canadians were associated with inadequate levels of sanitation and hygiene and a shortage of domestic water. Bjerregaard and Young's (2008) research among the Inuit (indigenous people) in the Arctic produced similar results. Inequality in access to water is the result of mutual interplay between geographical conditions, technology and a society's socio-political arrangements (Bisung & Elliot 2014; Swyngedouw, 2009). Daley et al. (2015) observed that the geographical location of hamlets in Arctic communities and the need for specific water technologies constrained these hamlets' access to water.

In a study conducted in Kenya ,where 42% of the population practiced open defecation, Bisung, Elliot, Abduho, Schuster-Wallace and Karanja (2015) found that structural factors such as unemployment, the unequal distribution of resources and a lack of trust in the leadership resulted in lack of access to water and sanitation. Unemployed young men engaged in sand harvesting which damaged the surroundings, causing mosquito infestation. Secondly, unemployment constrained financial contributions to communal projects such as the construction of sanitation facilities. In addition, community members could not afford water treatment products as well as products such as soap that are required for hygiene. Finally, due to unemployment, community members were unable to participate in community activities to solve water and sanitation problems as they left home early in the morning to search for casual work and returned late in the evening. Thus, in addressing issues pertaining to access to water, it is important to examine the environmental, social, economic and political context that determines such access.

Inadequate sanitation poses unique health risks to women, including increased risk of maternal mortality from unhygienic birthing practices, poor infection control and uro-genital tract infections (Cheng, Schuster-Wallace, Watt, Newbold & Mente, 2012; Mudey, Kesharwani, Mudey & Goyal,

2010). Women living in slums are forced to walk long distances or wait in long queues because water sources in these areas are limited to public connections and water is highly regulated or is only supplied at specific times (Hunter, MacDonald & Carter, 2010; Bartram & Cairncross, 2010). Sahoo et al.'s (2015) study among women in India found that sanitation practices included not only defecation and urination but carrying water, washing, bathing and menstrual management. Women who practiced open defecation reported having to walk long distances to find locations with sufficient water for bathing and anal cleansing. Women who carry water for long distances such as to places of defecation face challenges when they are ill or suffer from a debilitating physical condition such as pregnancy (Sultana & Crow, 2000). Furthermore, women who access shared sanitation facilities report that the latrines are usually dirty, are located outside their homes and lack a bathing or changing room (Corburn & Hildebrand, 2015).

2.3.1 Water, sanitation and hygiene in South Africa

South Africa is a middle-income, developing country characterized by unequal income distribution. Income disparities are reflected in the provision of basic services such as water and sanitation (United Nations [UN], 2005). The Strategic Framework for Water Services addresses the whole spectrum of water and sanitation issues (Department of Water Affairs [DWAF], 2003). Urban areas are faced with the challenge of informal settlements which have mushroomed as a result of rural-urban migration in search of jobs (Marx & Charlton, 2003). Informal settlements in South Africa are characterized by high population density, inadequate water and sanitation and poor health conditions (UN, 2005).

In Durban alone an estimated one million people live in densely populated settlements. Although safe water and appropriate sanitation is a basic human right in South Africa (Makaudze et al., 2012) close to six million South Africans do not have access to safe drinking water (DWAF, 2008). Furthermore, the pace of sanitation delivery is low; according to the national 2012 report on the status of sanitation, 11% of South African households do not have access to sanitation services. Water-related diseases such as diarrhea are said to claim 13 600 lives each year (Manase et al., 2009). The standard for a basic water supply set in the Reconstruction and Development Programme (RDP) in South Africa is 25 L of potable water per person per day within 200m of each dwelling (Potgieter et al., 2007). However South Africa is facing the challenge of low water coverage, especially in rural areas (Manase et al., 2009).

In Mvunyane, KwaZulu-Natal, 43% of households reported that they use less than 50 L of water per day and 49% reported that they use 50 L to 100 L a day (Manase et al., 2009). Moreover, given the average number of people per household, an average quantity of 15 L per capita per day is much less than the recommended 25 L (Manase et al., 2009). A study conducted in Durban found that people in informal settlements did not feel that communal sanitation facilities offered improved health benefits. The researchers found that while residents were pleased to receive a sanitation unit, with time they lost the motivation to maintain these toilets which then became dirty and were perceived to have low health benefits (Roma, Buckley, Jefferson & Jeffrey, 2010).

Approximately 21 million South Africans do not have access to adequate sanitation. Inadequate methods include the bucket system, pit toilets and poorly designed water-borne sewage systems (National Sanitation Policy, 1996). Potgieter et al. (2007) found that people that lacked adequate sanitation and were waiting for government to provide ventilated improved pits (VIP) resorted to building their own VIP latrines. However, these latrines provided neither safety nor privacy as they were not built according to the VIP guidelines. The toilets were shallow, were prone to collapse due to heavy rains or wind, and insects and odor were ever-present (Potgieter et al., 2007). Such facilities pose a threat to both the general population and PLWHA (Potgieter et al., 2007).

Inadequate sanitation has a general health impact on a population. Poor sanitation has a significant impact on the quality of life as well as a community's education and development opportunities (National Sanitation Policy, 1996). The sanitation sector in South Africa is faced with the challenge of the ongoing growth of formal and informal settlements particularly in urban areas due to rural-urban migration, and population growth as well as an increase in the number of foreign nationals resident in the country (Report on the Status of Sanitation Services in South Africa, 2012). In 2009, there were approximately 2,500 informal settlements with 1.2 million households (Report on the Status of Sanitation Services in South Africa, 2012). This poses a significant challenge to the water and sanitation sector.

2.4 Home and community-based care

The WHO defines HBC as “the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death” (2001). Home-based care consists of formal and informal components; formal components comprise of healthcare professionals such as

doctors and nurses who admit patients to HBC and visit them when the need arises, while the informal component consist of family members of HIV/AIDS clients who are the primary care givers (Rödlach, 2009). Finally, there is a group of individuals who are trained to offer care for individuals living with HIV/AIDS. They provide a link between the informal and formal aspects of HBC by linking the clinic to the home. Such individuals are also referred to as community care givers or volunteer care givers (Jacques & Stegling, 2004; Marston, 2003).

Community Health Workers are defined as “members of a particular community whose task is to assist in improving the health of that community in cooperation with the health care system or public health agencies” (Johnson & Khanna, 2004, p. 497). Research shows that that there is a gendered bias in care giving, with the majority of volunteer care givers being female (Akintola, 2006; Rodlach, 2009; Naidu & Sliiep, 2012). Hundreds of lay individuals are being trained as CHWs in response to the HIV/AIDS pandemic and are providing care to the sick, especially in rural areas where medical facilities are scarce (Johnson & Khanna, 2004).

Care givers perform specific duties in HBC. In the final stages of AIDS, patients are weak and care givers perform duties such as feeding them and in some cases preparing food, bathing patients and washing soiled linen and clothing. Home-based care also includes administering anti-retroviral drugs (ARVs) (Potgieter & du Preez, 2012). In 1994, the Ministry of Health in Botswana institutionalized the Community Home-Based Care (CHBC) program as one way of relieving the pressure of growing numbers of HIV/AIDS hospitalized patients (Ngwenya & Kgathi, 2006).

The national estimate of HIV prevalence in South African in 2012 was 12.2% (Shisana et al., 2014). The huge burden of HIV/AIDS on the South African public health system prompted the government to adopt a policy on HBC for PLWHA (Department of Health [DOH], 2001). Patients suffering from HIV/AIDS or HIV-related illnesses are discharged from hospital after a short while or not admitted at all to be cared for at home (Potgieter & du Preez, 2012). Home-based care is an alternative to traditional clinic-based HIV care programs, especially where public health services are strained (Estopinal et al., 2012).

2.4.1 Challenges faced by Home and Community-Based Care Organizations

Home and community-based care organizations are facing many challenges. A study conducted in Nigeria revealed that the prevalence of public health workers in HBC was low (16%) (A Moran, Oguniola, Salako & Alausa, 2012). Furthermore, home and community-based care organizations

are not receiving sufficient support from the government; this was evident in Zimbabwe where it was reported that from the late 1900s the programs were greatly dependent on churches, non-governmental organizations (NGOs) and community resources (Rödlach, 2009). Similarly, in South Africa, community-based organizations (CBOs) have limited funds to run HBC programs and rely on foreign donors (Johnson & Khanna, 2004).

In addition, there are limited funds for CHWs, many of whom volunteer for this work due to unemployment or because they feel a sense of responsibility to their communities that are overwhelmed by the HIV pandemic (Ledwaba, 2005). A lack of government commitment to home and community-based care hampers the smooth running of organizations that care for HIV/AIDS clients.

Kang'ethe (2008) found that 50% of the HBC kit components recommended by the government were missing in home and community-based care. Akintola and Hangulu (2013) concluded that there was a poor supply of protective material and that what was provided was of poor quality; consequently CHWs resorted to either performing their duties without protective gloves or re-using materials and in some cases improvising by using plastic bags. In addition many CHWs have not been adequately trained to care for HIV/AIDS clients (Akintola & Hangulu, 2013; Kang'ethe, 2008; Potgieter & du Preez, 2012). This affects their performance. For example if a CHW has limited knowledge of hygiene, they risk contracting HIV, TB or other infectious diseases while caring for their clients and they also put the client at risk of contracting opportunistic diseases. Another challenge is poor waste storage, leading to inefficient management of clinical waste and failure to maintain good sanitation and hygiene (Kang'ethe, 2008).

2.4.2 Water, Sanitation and Hygiene in Home and Community-Based Care

Water is a crucial factor in caring for PLWHA. A study conducted in Nepal found that those that contracted HIV used more water for drinking, using the toilet/sanitation and bathing (WaterAid report, 2010). Ngwenya and Kgathi (2006) found that HIV/AIDS clients need an additional 20-80 liters of water depending on the severity of their symptoms. An adequate water supply and sanitary facilities are of the utmost importance if PLWHA are to remain healthy for as long as possible. Safe water is important because PLWHA are susceptible to water-borne diseases due to their compromised immune system (USAID, 2004). It is estimated that diarrhea affects 90% of

HIV/AIDS patients and results in significant morbidity and mortality rates (Makaudze et al., 2012). Diarrhea reduces the rate of ARV absorption (WaterAid report, 2010).

In HBC care, water is needed to take medication, for bathing clients, washing soiled clothing and linen and for essential hygiene purposes which reduces exposure to infection (Potgieter et al., 2007). Water is used to make food easier to eat for patients suffering from mouth ulcers or thrush and for hygiene to prevent opportunistic infections (Yallem et al., 2012). It is also used by HIV positive mothers to prepare formula for their HIV-negative infants (Manase et al., 2009). Moreover, water is needed to sanitize the HBC environment and eliminate odor for the comfort of patients and visitors as this may affect the wellbeing of patients and CHWs (Ngwenya & Kgathi, 2006).

The unavailability of water interferes with the day-to-day activities of HBC. Sixty six per cent of CHWs in Botswana reported that water shortages hampered their daily activities (Ngwenya & Kgathi, 2006). They reported cutting down on the number of times they bathed patients during water shortages or offering dry baths.

Moreover, it is crucial that human feces are properly disposed of in home and community-based care. This reduces the chances of PLWHA contracting opportunist diseases. Kang'ethe (2006) found that clinical waste was being dumped in pit latrines or council bins or was thrown into the bush. If waste material is not properly disposed of it poses a health risk to the community and PLWHA. Animals that are attracted to solid waste scavenge in the rubbish. Moreover, children come into contact with clinical waste in the play grounds. Animals come into contact with people after exposure to bacteria and children come into contact with their family at home. HIV-positive family members are more likely to contract opportunistic infections due to their weak immune system. Toilets should be in close proximity to homes, especially for weak patients. This makes it easier for CHWs to care for their patients. Good sanitation facilities also protect clients' dignity as well as their health (Potgieter et al., 2007).

Knowledge of how to safely handle, transport and dispose of healthcare waste is the key in maintaining hygiene. Community health workers provide bed baths and oral hygiene, care for sores and wounds, change diapers, clean vomitus and offer physical therapy (Akintola, 2011). All these activities require direct contact with the patient's body fluids; hence knowledge of how to maintain hygiene in HBC is crucial. Research shows that CHWs are not given adequate training with regard

to these issues (Akintola & Hangulu, 2013; Kang'ethe, 2008; Potgieter et al., 2007). Kang'ethe (2008) recommended that one way of ensuring that hygienic practices are followed in home and community-based care is to appoint knowledgeable program managers and adopt strong and functional policies on handling clinical waste.

In conclusion, the literature notes that water and sanitation are crucial in maintaining health. Given that the UN, WHO and UNICEF aim to improve health in developing nations, the issue of inadequate water and sanitation cannot be overlooked. Consequently, this study advocates that CPHC should be revisited and that the provision of water and sanitation should be placed at the top of the development agenda of developing nations.

2.5 Theoretical framework

2.5.1 The ecological systems theory

This study employed the ecological systems theory as its main conceptual framework (Figure 2.1). The theory was developed by American Psychologist, Urie Bronfenbrenner (Härkönen, 2001). This theory of human development that combines ecological principles and systems theory (Wilder, 2009) was introduced in the 1970s (Bronfenbrenner, 1994). The ecological environment is perceived to have nested structures; each inside the other, moving from the inner level to the outside, namely, the micro-, meso-, exo-, and macro-systems. The chrono-system was added more recently (Bronfenbrenner, 1994). The ecological systems theory was later renamed the bio-ecological systems theory to emphasize the child's own biology as a primary environment that fuels development (Paquette & Ryan, 2001). The ecological systems theory is based on the proposition that human development takes place through complex reciprocal interactions between the individual and their immediate environment (Bronfenbrenner, 1994).

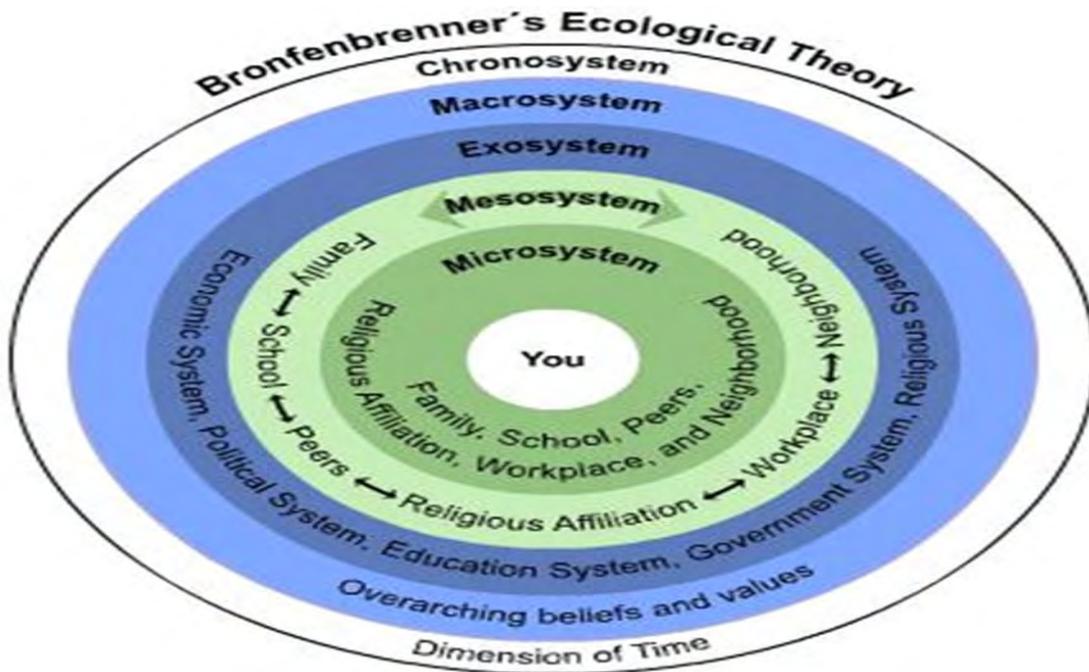


Figure 2.1: Bronfenbrenner's ecological theory for human development (Bronfenbrenner, 1974)

The word ecology stems from the Greek words *oikos* which means house or environment and *logos*, which means knowledge (Härkönen, 2001). Hence, from a biological perspective, the ecological system is the study of living organisms in their natural environment (Härkönen, 2001). The word system is representative of a systems structure and not something which is systematic. Bronfenbrenner studied the dependency between man and environment; his theory is also used to describe human socialization (Härkönen, 2001). It is assumed that a person is an active player, exerting influence on the environment and that the environment compels the person to adapt to its conditions and restrictions (Bronfenbrenner, 1979). Consequently, the environment is a nested structure (system) which the individual constantly interacts with. Moreover, the environment impacts on the individual in both positive and negative ways (Wilder, 2009).

The ecological systems theory is closely related to the meta-paradigm in the field of social work, generally referred to as person in environment (Wilder, 2009). From this perspective, an individual is examined in terms of how well they fit in their environment. This paradigm is based on the assumption that when a person is connected and engaged with a supportive environment, this leads

to improved functioning (Wilder, 2009). While the ecological systems theory was developed to explain human development, it has been used and adapted to other fields.

In health promotion, the ecological systems theory has been used to explain infection control in HBC for PLWHA/TB (Akintola & Hangulu, 2014). It has also been applied in research to understand the experiences of family caregivers taking care of elderly adults and caregivers' perceptions of financing community-based long-term care (Davis, 2009; Wilder, 2009). As highlighted above, the ecological systems theory works from the assumption that an individual's functioning is improved when they are engaged and connected to a supportive environment (Wilder, 2009). Hence, in relation to the current study, one would assume that CHWs would be able to provide better care to HIV/AIDS clients if their environment afforded them access to water, sanitation and hygiene.

2.5.2 Levels of ecological systems theory as applied to the present study

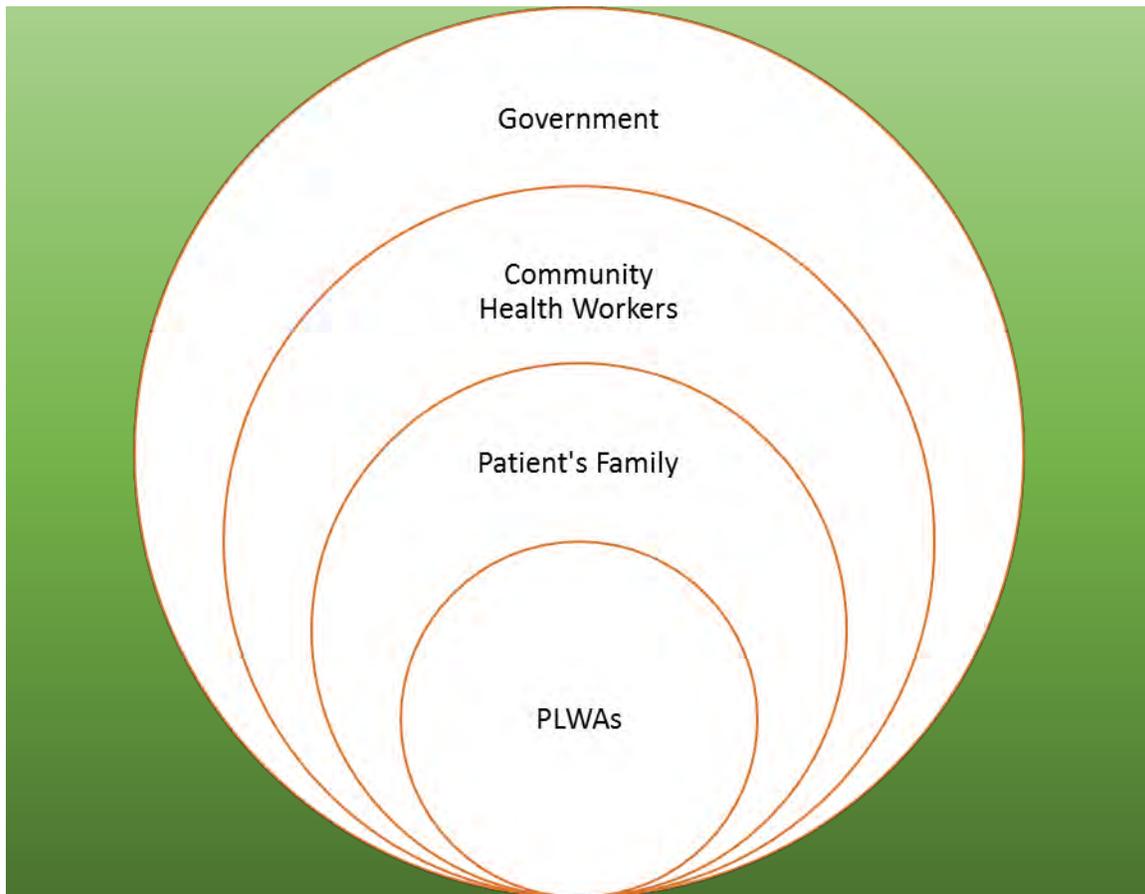


Figure 2.2: Bronfenbrenner's ecological systems theory as applied to the study (Bronfenbrenner, 1974).

Bearing in mind that the ecological systems theory has the five levels listed earlier, namely the micro-, meso-, exo-, macro, and chrono-systems, for the purpose of this study the focus was on the first three levels, the micro-system, the meso-system and the exo-system (Figure 2.2). The ecological systems theory helped to shed light on how WASH affect HIV/AIDS clients at the micro-level, family members of HIV/AIDS clients at the meso-level and volunteer caregivers at the exo-level in HBC. In turn, this highlighted how WASH at these three levels affect the wellbeing of HIV/AIDS clients. The three levels are discussed below.

2.5.3 The micro-system

The micro-system refers to the pattern of activities, social roles and interpersonal relations of an individual with particular physical, social, and symbolic features that can either enable or inhibit more complex interactions with the environment (Bronfenbrenner, 1994). At the micro-level, WASH were explored to determine how they influenced and were influenced by the lives and wellbeing of PLWHA. The HIV/AIDS client is the individual at the micro-level; he/she has face-to-face interactions with different social agents such as his/her own immediate family, other members of the community and caregivers. An insufficient water supply and poor sanitation and hygiene practices pose challenges in keeping the house clean as soiled linen may be kept in the house for long periods. Consequently, members of the community may be reluctant to visit HIV/AIDS client's homes as they may feel that such households are not hygienic and smell bad. Thus, HIV/AIDS clients with WASH challenges become isolated and lack the spiritual and social support required for their recovery (Ngwenya & Kgathi, 2006). This example highlights how circumstances in the environment (WASH) can either enable or inhibit interactions between the individual (HIV/AIDS client) and the immediate environment.

2.5.4 The meso-system

The meso-system comprises linkages and processes between two or more settings containing the individual (Bronfenbrenner, 1994). Family experiences are related to peers' experiences and peers' experiences to neighborhood experiences, indicating that they interact with each other. This level explains how the attitudes and beliefs of social agents affect and shape the actions/behaviors of HIV/AIDS clients. Thus, the meso-system shed light on the different belief systems, attitudes, behavior and practices of family members and peers of PLWHA with regard to WASH and how this impacted on the clients. The researcher explored how WASH practices influenced and were influenced by peers and family members of PLWHA. PLWHA use about 20-80L more water than the average person; hence, in circumstances where there is limited water the caregiver uses more water for their client, leaving little for other family members (Potgieter & du Preez, 2012). This can cause hostility between family members and the HIV/AIDS client. Family members might discourage the caregiver from visiting because of the burden of having to fetch more water especially in cases where they have to travel long distances. Family members also hold particular beliefs and attitudes relating to hygiene. Some are uncomfortable with caregivers using gloves when attending to their family member because they feel that they will feel unloved (Akintola,

2004). This may lead to caregivers avoiding that house as they do not want to put themselves at risk of contracting HIV/AIDS/TB. The family is thus not able to get the help they need. In turn, the caregiver is isolated and worried about the wellbeing of his/her HIV/AIDS client (Ngwenya & Kgathi, 2006).

2.5.5 The exo-system

The exo-system consists of linkages and processes between two or more settings (Bronfenbrenner, 1994). At least one of these settings does not constitute the individual; however, events that occur in this setting directly influence the individual (Bronfenbrenner, 1994). The exo-system is an accumulation of all the levels. This is the level that comprises of HBC organizations where caregivers belong. At this level, the researcher explored how WASH affected volunteer caregivers and how this in turn affected their work which impacted on HIV/AIDS clients. The impact of government and policies on WASH practices in HBC was also examined. Policies on WASH were explored. Organizations that offer HBC need to familiarize themselves with policies on WASH and educate caregivers on how to care for HIV/AIDS clients. This will enable volunteer caregivers to perform their duties while adhering to hygienic practices. Moreover, caregivers require education on how much water PLWHA should drink and the importance of water in general to HIV/AIDS clients. Hence, if water is in short supply, caregivers should not give HIV/AIDS clients water from sources (river) that may not be safe. Kamminga and Wegelin-Schuringa (2003) note that there is need to address HIV/AIDS in water and sanitation policies as there is a lack of systematic, in-depth information on the relationship between HIV/AIDS and WASH. Makaudze et al. (2012) found that there is a need for government to increase the availability of boreholes in rural areas, as a significant number of PLWHA do not have access to safe water.

Finally, it should be noted that the micro-system, the meso-system and the exo-system are interdependent and interact with each other; such interaction was explored among these levels.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

This chapter presents the research methodology employed for this study. It describes (a) the context in which the research took place, (b) the design of the study, (c) a comprehensive description of the participants and the process used to select them (d) data collection methods and (d) how the data were analysed. A detailed table is presented that highlights the characteristics of the participants and HBC organizations that participated in this study (Table 1.1).

3.2 Research context and setting

The research study was conducted in Durban, the largest city in the KwaZulu-Natal province of South Africa. It is located on the eastern coast of South Africa with an approximate population of 3.5 million (Marx & Charlton, 2003; Stats SA, 2007). Durban forms part of the eThekweni Metropolitan Municipality that covers an area of 2,300km². According to the eThekweni Municipality (2002) 18% of the settled area is occupied by formal households, 5% by informal households and 10% by peri-urban settlement. It is estimated that 33% of the total metropolitan population lives in informal settlements; this population is overwhelmingly African. Moreover, it is estimated that almost half of the entire African population in eThekweni Municipality lives in informal dwellings (Marx & Charlton, 2003). The study was conducted on four non-profit community organizations known as HBC organizations located in four peri-urban communities on the outskirts of the Durban Metropolis. These organizations were established in marginalized communities to deal with the social issues faced by community members and to also offer care to individuals suffering from various diseases, including HIV/AIDS. Two of the organizations were located in Umlazi, the third largest township in South Africa, while the other two were located in the Folweni and Cato Manor peri-urban communities, respectively. Community health workers (participants) were drawn from three CBOs. I was unable to schedule an appointment with CHWs at one of the organizations despite many attempts during the time period of the study. Data were collected over a period of three months (November 2014 - February 2015). Information on the participants and the nature of the CBOs is set out in Table 1.1.

3.3 Design of the study

The theoretical framework for most qualitative research emerges from an interpretivist perspective (Ulin, Robinson & Tolley, 2012). This study was informed by an interpretative paradigm. A paradigm is a worldview or a framework for theory and research and includes basic assumptions, key issues, models of quality research and methods for seeking answers (Neuman, 2014). The interpretative paradigm is concerned with how people interact and get along with one another. It includes a systematic analysis of socially meaningful action through direct, detailed observation of people in their natural setting (Neuman, 2014, p.104). The interpretative approach allows a researcher to explore and understand phenomena through observation of participants' behavior and participating in their activities (Snape & Spencer, 2003; Creswell, 2013).

The interpretative approach enabled the researcher to apply methods such as interviews with project managers/founders of CBOs on their experiences of issues relating to WASH based on the reports they receive from CHWs. Using the interpretative approach, the researcher was able to not only observe behavior as it occurred in its natural setting but to participate in activities with the CHWs as they performed their daily activities of HBC.

The purpose was to gain an in-depth understanding of the lived experiences of CHWs with regard to WASH in community-based care. Thus, a qualitative approach was preferred to the quantitative method due to its ability to elicit rich, descriptive data and to allow participants to respond in their own words and language (Guest, MacQueen & Namey, 2012). Bryman (2004) highlights that qualitative research emphasizes the importance of individuals' personal and social meanings of phenomena and enables the researcher to explore deeper into the participants' lives.

Kothari (2011) defines a "research design as the arrangement of conditions for collection and analysis of data in a manner that aims to combine relevance to the research purpose with economy in procedure" (p. 31). Due to the explorative nature of the study, a qualitative research design was appropriate because of its flexibility in allowing consideration of different aspects of the phenomena under study (Kumar, 2012). The qualitative research design enabled the researcher to explore WASH in HBC from the perspective of CHWs and project managers. Moreover, qualitative research involves understanding individuals' lives by examining their perspectives in context. It emphasizes the importance of context in understanding the phenomenon of interest

(Heppner, Wampold & Kivlinhan, 2008). The qualitative design enabled me to gain a deep understanding of the CHWs' experiences with regards to WASH.

Qualitative research enables a researcher to study phenomena in an in-depth and open manner, paying particular attention to detail as the researcher identifies and attempts to understand classes of information that emerge from the data (Blanche, Durrheim & Painter, 2006). The use of a qualitative design for this study enabled the production of rich, explanatory and descriptive data in order to understand:

- a) CHWs' perceptions of WASH in community and home-based care;
- b) Experiences of WASH among PLWHA and their family members through the lens of CHWs; and
- c) The implications of WASH for the wellbeing of PLWHA, their immediate family and CHWs.

3.4 Study sample

The CBOs were identified through snowball sampling which is discussed later in this chapter. Permission to access the research site was requested from the founders or managers of the CBOs that acted as gatekeepers. According to Neuman (2014), gatekeepers are “people with the formal or informal authority to control access to a site” (p. 441). After the organization was recruited, each met with all their CHWs to inform them about the study; project managers were in charge of informing the CHWs about the study as well as introducing me to them. The detailed characteristics of the participants is displayed in the diagram below.

Organization	Location	Year founded	Employee's status	Gender	Age	Participants in FG	Service in HBC (Years)	Participant's age range in FG (Years)
CBO-A	Umlazi Township	2004	Founder	Female	42	5	6M-1	20-44
CBO-B	Folweni Township	2000	Founder	Female	65	12	1-5	27-52
			Manager	Male	27			
CBO-C	Umlazi Township	2003	Manager	Female	42	12	8M-8	24-58
		Registered				9	6-13	26-54
		2005				11	7M-5	19-52
CBO-D	Cato Manor Township	2006	Founder	Female	50	0	-----	-----
Total Number of participants = 54								

Table 3.1: Summary description of participants and HBC organizations

Note¹

3.4.1 Selection of study Participants

The researcher used a non-probability sampling technique to recruit CBOs, a method influenced by the interpretative approach. Non-probability sampling allows for a sample that best fits the purpose of the study (Neuman, 2011). It allows for a case to be selected on the basis of a specific context (Neuman, 2011). Hence, the researcher selected this sampling technique in order to capture the unique qualities of CHWs. This unique quality is that this study specifically sought to explore

¹ Letters are used in place of the names of the organizations to ensure anonymity. M stands for months.

CHWs' experiences with WASH since they have first-hand experience of PLWHAs and their immediate family members.

Within the non-probability sampling technique, the researcher used a combination of purposive and snowball sampling to recruit CBOs. Purposive sampling, also referred to as judgemental sampling, is a sampling technique used by an expert to select cases with a specific purpose in mind (Neuman, 2011). The researcher used purposive sampling because it was able to produce unique cases that were especially informative for the purpose of this research. I purposefully recruited CBOs that offer care to PLWHAs. Furthermore I used the snowball sampling method to recruit more organizations. Ulin et al. (2012) note that, "Snowball sampling is a technique for locating informants by asking others to identify individuals or groups with special understanding of a phenomenon" (p. 58). This technique was chosen based on the fact that I did not have previous experience of working with HBC organizations.

3.4.2 Study Participants

The goal of qualitative research is to produce rich data and the sample is chosen based on the participants' ability to produce in-depth understanding of phenomena under investigation (Ulin, et al., 2012). In light of the above, CHWs and the managers/founders of HBC organizations were selected as study participants. These participants were chosen based on their ability to provide rich information on their experiences with WASH in community-based care (Davies, 2007). Five project managers/founders were recruited as they oversaw the HBC care program and had insight into what was happening with regard to water and sanitation in community-based care. This came about as a result of their direct interaction with CHWs that provided daily and weekly reports to project managers/founders about what was happening in the field including the challenges they faced. In addition, project managers were included in the study based on the fact that some had served as CHWs before being promoted to management positions and were hence knowledgeable about the study topic.

According to Patton (2002), a researcher needs to engage with the people who experience the phenomenon of interest in order to collect qualitative data. The researcher opted for a homogenous sample; this type of a sample was appropriate because it allowed the researcher to study a group in-depth and to focus on an issue that was relevant to all the participants (Ulin et al., 2012). The second group of participants was CHWs that had first-hand experience of PLWHA as they

provided care for them on a daily basis. Community health workers were deemed to be best qualified to provide insight into the study topic as they had first-hand experience of WASH in HBC. The criteria for the participation of CHWs was that they had volunteered to work with the HBC organization, provided home care to someone with HIV or clinical AIDS; had offered care for a minimum period of six months; and were willing to share their experiences with regard to WASH in home and community-based care.

3.5 Data collection procedure

3.5.1 Data collection methods

According to Ulin et al. (2012), data collection methods refer to a systematic approach to data collection. Data collection is the manner in which information for research is generated (Flick, 1998). There are two broad approaches to qualitative data collection. The first focuses on naturally occurring data while the other generates data through the research intervention (Ritchie & Lewis, 2003). This study used both approaches to gather information. Naturally occurring data was obtained through participant observation and data generated through the research intervention was achieved through one-on-one in-depth interviews with project managers and focus group discussions with CHWs. This is known as triangulation that collects data in as many different ways as possible or from different sources. This method was selected because I wanted to capture the richness, texture and feeling of a dynamic social life (Neuman, 2014). Hence, immersing myself fully in a range of data while paying attention to insights throughout the process was one way of achieving this goal.

3.5.2 Focus group discussions with Community Health Workers

Focus group discussions were conducted to gain an understanding of the experiences of CHWs with regard to WASH. A focus group is a qualitative research technique where people partake in group discussion (Neuman, 2014). Focus groups are more relaxed and are regarded as informal interviews (Neuman, 2014). They allow the participants to open up, challenge one another and explain their responses to one another. The participants' language and their general understanding of phenomena are spontaneously displayed and their perspective is less influenced by interaction with the researcher than might be the case in a one-on-one dyadic interview (Ritchie & Lewis, 2003). Focus groups are synergistic in nature; the group works together and this interaction is used to generate data and insight (Stewart & Shamdasi, 1990). This was an advantage to the researcher

because focus groups were able to “provide insights to formation of views that cannot be readily achieved via individual interviews” (Somekh & Lewin, 2005, p. 42).

Focus group discussions also create an atmosphere that enables members of a social group that is marginalized to freely express themselves (Neuman, 2014).

Focus group discussions took place in open spaces/room at the centre that operated as board rooms. Most of the home-based organisations had one big open area/room where meetings and group discussions took place. This was the same space that was granted to us to conduct focus group discussions. The participants, the research assistant and myself sat on chairs arranged in a circle. The research assistant was guiding the discussion in IsiZulu by posing and open ended question and allowing the participants to engage with a specific theme. During the discussions I observed the participants and also operated the audio recorder and took notes when necessary. All the interviews were recorded using the audio recorder and later transcribed verbatim into English by the research assistant.

3.5.3 In-depth interviews with home-based care managers

The main aim of this study was to understand the lived experiences of CHWs with regard to WASH in community-based care. After conducting the focus group discussions with CHWs, I conducted interviews with project managers to gain insight into their perspective as well as to follow up on some of the issues raised during focus group discussions that needed further exploration. In qualitative research, the researcher is the key and primary instrument in the data collection process and assumes the dual task of data collection and analysis (Davies, 2007). I took time to learn the skills necessary to become an effective interviewer before entering the field. These skills include “listening, following up on what the participant is saying, avoid leading questions, tolerate silence and allow the interviewee to be thoughtful” (Blanche & Durrheim, 1999, p. 130). In-depth interviews are described as a “meaning-making partnership between interviewers and their respondents” (Hennink, Hutter & Bailey, 2011, p. 109). Consequently, the researcher and the participant were collaborators, co-creating knowledge and meaning in the interview setting (Ulin et al., 2004). During the interview it is important that the researcher creates a balance in the way they ask questions such that the interview unfolds like a natural conversation and a question and answer session (Blanche & Durrheim, 1999). In-depth interviews allowed the project managers

to express their personal opinions on and experiences of WASH and their knowledge that emanated from reports from CHWs as well as occasional visits to the field.

I conducted the in-depth interviews with the HBC project managers. The interviews were conducted in the offices of project managers at the center or any space available at the time that I was there such as the kitchen or in the passage leading to another office at the organization. I used an interview guide with themes to add structure to the interview. I engaged with the participant by asking them open ended questions about their experiences with regards to water, sanitation and hygiene while reflecting and probing on what they were saying.

3.5.4 Participant observation

Participant observation is a method that is rooted in ethnography. The term ethnography literally means ‘writing about people’. Ethnography emphasizes the importance of the researcher getting involved in the social world of the participant in order to determine how they view the world (Goldbart & Hustler, 2005). For this study, which sought to understand CHWs’ experiences of WASH in community-based care, I used participant observation in addition to the methods discussed above to gain additional insight through experiencing the phenomena first hand (Ritchie & Lewis, 2003). Participant observation provides “direct experiential and observational access to the insiders’ world of meaning” (Jorgenson, 1989, p. 15). Through participant observation I was able to observe and record events, actions and interactions as they unfolded in their natural setting which was the homes of the patients and their community.

3.5.5 Data collection instrument

The interviews with project managers and focus group discussions with CHWs were guided by an interview guide with open-ended questions. According to Neuman (2011), a semi-structured interview is a type of interview technique that uses mostly open-ended questions so as to obtain rich and descriptive information from participants. I opted for an interview guide for both project managers/founders and CHWs because it allowed issues to be specified in advance, enabling the interviewer to decide on the sequence and wording of the questions during the course of the interview. Moreover the outline renders data collection systematic and the interviews remain fairly conversational and situational (Ulin et al., 2004). I used the three types of questions identified by Rubin and Rubin (2011), that is, the main question, followed by follow-up questions and probe questions (Appendix C). Since the study was informed by the ecological systems theory, questions

were developed for each level (micro-, meso- and exo-levels). The focus group guide for CHWs and semi-structured interview guide for project managers were very similar with slight differences. These guides were developed after an extensive review of the literature on WASH in HBC. While both guides were constructed in English, the focus group guide was later translated in IsiZulu by an IsiZulu speaking research assistant.

3.6 Method of analysis

Even though a specific stage is dedicated to analysis, in qualitative research analysis is an on-going process that begins while gathering data (Neuman, 2014; Spencer, Ritchie & O' Connor, 2003). In this study, the qualitative data stemmed from the extensive field notes recorded during participant observation, and the transcripts from the individual interviews and focus group discussions (Spencer et al., 2003). Many pages of information were generated by the recordings. Data reduction was achieved by the method described by Braun and Clarke (2006) as thematic analysis. Flexibility is one of the many benefits of thematic analysis. It has the ability to interpret various aspects of the research topic and also allowed the researcher to analyse data using the theory that informed the study, ecological systems theory. Thematic analysis is defined as a method of identifying, analysing and reporting patterns (themes) within data (Braun & Clarke, 2006).

The researcher followed the six steps described by Braun and Clark (2006) to arrive at the findings. Preliminary analysis began during the planning of the interviews and focus group discussions as well as during the first field activities of data collection. As described by Braun and Clark (2006), firstly, all transcripts were read thoroughly. I familiarized myself with the data by reading and re-reading the data and noting down initial ideas. As I immersed myself in the data by reading and re-reading, I paid careful attention to the emerging themes and started to attach labels to the chunks of text that represent these themes (Ulin et al., 2012). Secondly, different codes were generated from the data. I coded interesting features of the data in a systematic fashion across the entire data set and collated data relevant to each code. I used the research questions to guide the coding process and used several codes around a specific topic (Hennink et al., 2011). Thirdly, I identified themes by collating the codes into potential themes, gathering all data relevant to each potential theme. Fourthly, I reviewed all the identified themes; data from certain themes were merged with more appropriate themes while developing new themes. In the fifth stage, the reviewed themes were

defined and named. Finally, all the themes were presented by selecting examples of vivid, compelling extracts. At the end of the analysis, a summary of the main themes, sub-themes and micro-subthemes was produced to capture the findings. This diagram is presented in chapter 4.

3.7 Ethical Considerations

Prior to data collection, ethical approval (Appendix A) was granted by the Ethics Committee of the University of KwaZulu-Natal. Informed consent was sought from the participants prior to commencing the focus group discussions and interviews. Participants were informed about the nature of the study, that participation was entirely voluntary, and their right to withdrawal from the study without any negative consequences and they were assured of confidentiality (use of pseudonyms) and anonymity (Appendix B). I also requested permission to take photographs during the period of data collection. All focus group discussions and in-depth interviews took place at the community-based care organizations. The interviews with project managers/founders were conducted in their offices except for one which took place at a convenient venue at the organization where meetings were held with CHWs. Focus group discussions took place in rooms that were available at the time. The interviews were conducted in English and took between 20 and 40 minutes. The focus group discussions were conducted in IsiZulu by a trained IsiZulu-speaking research assistant and lasted between 40 and 70 minutes.

3.8 Trustworthiness of the study

Rigor in this study was achieved through credibility, dependability, confirmability and transferability (Golafshani, 2003). Credibility, also known as the truth value was achieved via the description of rich data which was substantiated with direct quotes from the interviews. To achieve dependability, I took careful consideration of the rules and conventions of qualitative methodology; for example, all my research questions were clear and in line with the purpose of the research. The concept of reflexivity was applied to achieve confirmability. This means that, as a co-participant, I was able to distinguish my own values from those of the participants by documenting my assumptions and biases that could influence the interpretation of data. Thus, I was able to accurately capture the participants' perspectives and experiences. Finally, transferability refers to the extent to which the findings can be transferred to other contexts or respondents (Barbie & Mouton, 2004). The results from this study reflect experiences of WASH in

the context of community-based care at the time the study was conducted. This information was collected from different organizations in different locations; thus, the findings are an accurate representation of WASH in community-based care. However, careful attention should be paid to contextual factors if the findings are to be transferred.

CHAPTER FOUR

Experiences of WASH by Community Health Workers in Community-based Care

4.1 Introduction

The study's findings are discussed using the ecological systems theory as the overarching conceptual framework, focusing on the first three levels, namely; the micro-system, the meso-system and the exo-system. Thick descriptions of the narratives are presented in this chapter with direct quotes from the interviewees. The chapter begins with a summary of the major themes and sub-themes in Figure 3.1 below to present a “visual picture” of the main findings.

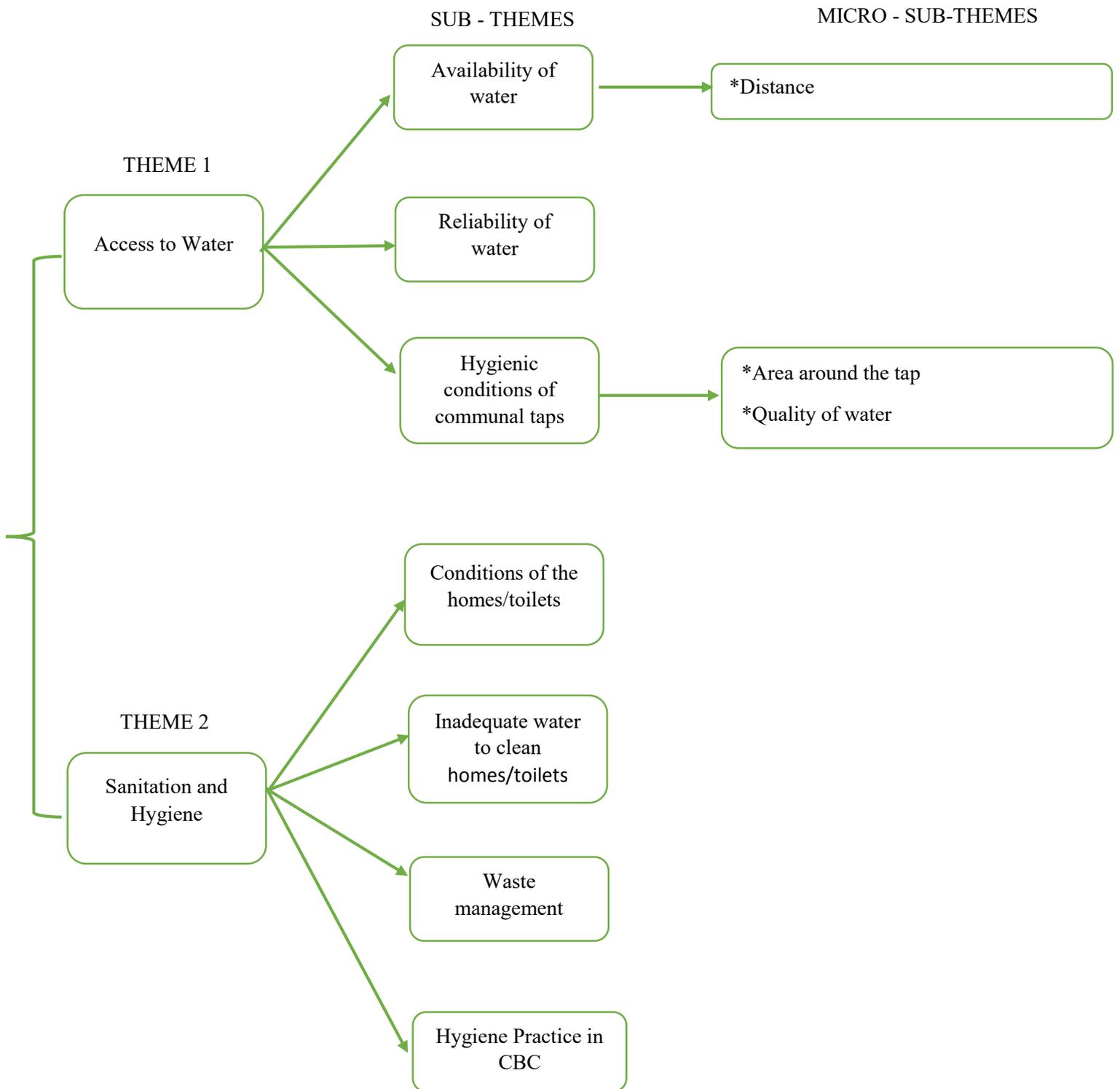


Figure 3.1: Summary of themes and sub-themes

4.2 Access to water

4.2.1 Availability of water

The availability of water can reduce the rate of infection in community-based care. Access to water is crucial to maintain cleanliness and hygiene in households with PLWHA/TB. In the communities under study, available water sources included running water in the homes, taps in the yard and communal taps. However, the majority of community members sourced their water from communal taps, especially in informal settlements (Figure 4.1). The distance from the household to the communal taps varied, with some households located right next to the communal tap while others were far away. One communal tap is meant to supply water to plus/minus 15 households; however, as a result of damaged communal taps there were situations where they would only be one communal tap for more than 100 households.

“They (community members) are living in shacks; they don’t have their own taps in their yards or wherever they’re renting. So they fetch water from communal taps, (Figure 4.1) those are the taps that are found on the road side.” (Founder #4)

Similarly, it was noted in the focus group discussions that access to water was a challenge because there were not enough communal taps. The ones that were provided had been vandalized and had not been repaired. The municipality had also shut communal taps down, with the intention of providing yard taps; however this process had been slow and had not yielded significant results. Community members also connected water illegally. Illegal water connections refer to the connection of water pipes to the communal standpipe that are meant to supply water to the community to people’s own yards. This reduces and sometimes halts the water pressure due to many people using it at the same time. The situation is worse during the weekends when everyone is at home.

“...we’re given taps in our communities ...but you find that there’ll be a time when there is no water, you can’t get water, maybe for a month or a few weeks and the person with HIV suffers.” (Focus Group 1)

In locations where households had yard taps or running water in their homes, some were without water because they could not afford to pay water bills. In such circumstances, household members fetch water from their immediate neighbors. It was reported that some neighbors at times refused

to supply water or charged for it. During the home visits, some patients reported being charged for water by their neighbors.

“In one household all the people who were working had died. The only people left were the grandmother, grandfather and the grandchildren. They could not afford to pay water bills. The municipality claimed the family had a huge debt and resorted to removing the water meter... so the family fetches water from the neighbors.” (Focus Group 3)

Distance

Community members indicated that, even though the municipality has provided communal taps within communities, the taps are located on the main roads; therefore, if houses are far from the main road, family members of PLWHA or CHWs walk a long distance to **access** water. Malfunctioning communal taps also result in people walking long distances to access the one tap that is functioning. Participants reported that they sometimes have to travel to other “sections” (areas in the township are demarcated by the municipality and are referred to as sections) to access water.



Figure 4.1: Communal standpipe

This presents a challenge in households with PLWHA, where household members have to walk far to access water for their loved ones.

“Sometimes you find that there is no water in the house and the standpipe is too far and you have a bedridden patient.” (Focus Group 3)

A participant in another focus group added:

“Communal taps are placed in the center of a demarcated area (section) or on the roadside and some households are neither close to any of these areas and family members have to travel long distances to access water.” (Focus Group 4)

CHWs feared for the patient’s safety when they had to leave them alone to fetch water. A weak patient might hurt themselves if they are left alone with no one to care for them. They added that they spent less time with their patients as much time is lost walking to the standpipe and waiting in the queue.

“A lot of things can happen while we are away to fetch water, sometimes it takes about two hours because there’s a lot of people at the taps. During this time something can happen to the patient, a patient may fall from the bed.” (Focus Group 4)

Moreover, patients that are weak cannot walk long distances and carry heavy buckets and containers.

In addition, CHWs reported that communal taps are often broken and are not fixed on time. It was reported that often only one communal tap out of five in a section would be working, leading to long queues. When no water is available in a particular section CHWs, PLWHA and family members travel long distances to other sections to **access** water.

“And when water runs out you may only find one of those taps is working; hence you end up having to walk a long distance to access this one tap. Sometimes we have to go to other sections to fetch water.” (Focus Group 2)

Another participant added:

“In the section where I live the one tap that was operating broke down and it was shut down (by the municipality) and removed from its place. Now when water runs out we have no tap nearby because there was only one remaining.” (Focus Group 2)

CHWs have many households to attend to and do not have the time to wait in the queues or walk long distances to fetch water, let alone spend a lot of time with their patients. As a result, in households that are experiencing water shortages, CHWs cannot bath or assist the patient because spending a long time queuing for water means that they are unable to visit their other patients.

“It happens that you need to bath a patient but there is no water and you cannot go out there (communal taps). At times there is not even another person who may go and fetch water for you and you end up having to leave without bathing the patient.” (Focus Group 1)

4.2.2 Reliability of water

At the beginning of the focus group discussion, most participants were quick to report that they did not have problems with water and that water was available. They did not realize that they had water problems. This could be due to the fact that this has become their way of life. When we probed further, they began to describe where and how they obtained water. It became apparent to us and to them that they do have issues with water. The water supply is unreliable and often runs out for days and sometimes weeks. The municipality then provides water using a tanker (Figure 4.2). The tanker stops at a certain spot where people have to go and fetch water. This presents a challenge to PLWHA as they have to walk to the truck and back with buckets of water and to CHWs who have to fetch water for their patients.

“The water is on and off; sometimes there is no water the whole day, even a week, so we go and fetch water from the standpipes and if there is no water there too, a truck from the municipality comes and delivers water to us.” (Focus Group 2)



Figure 4.2: A water tanker delivering water in the community

When a patient suffering from AIDS is not bathed, this affects their quality of life and consequently their well-being. The lack of water makes it difficult for primary caregivers to live with patients as patients need to be constantly cleaned. They are sometimes left the whole day without being cleaned as a result of the unavailability of water. This also has an impact on CHWs who said that they feel bad when they have to leave a patient without bathing them.

4.2.3 Hygiene conditions of communal taps

Areas around the taps

Given the limited number of communal taps, they are overcrowded and the areas around the taps are dirty and unhygienic (Figure 4.3). Fetching water from such sources can create the risk of infection that affects the wellbeing of PLWHA, their family members and CHWs.

“The area around the tap is in a poor condition, it’s really... muddy and dirty because others wash there and because different types of people go there. Others are clean and others are not so clean, they wash there and do everything there, causing chaos, but because you need water you just get it and go home.” (Focus Group 1)

Different activities are performed at the communal taps by different people, including washing clothes and linen and washing dishes. This results in the area surrounding the tap becoming dirty.

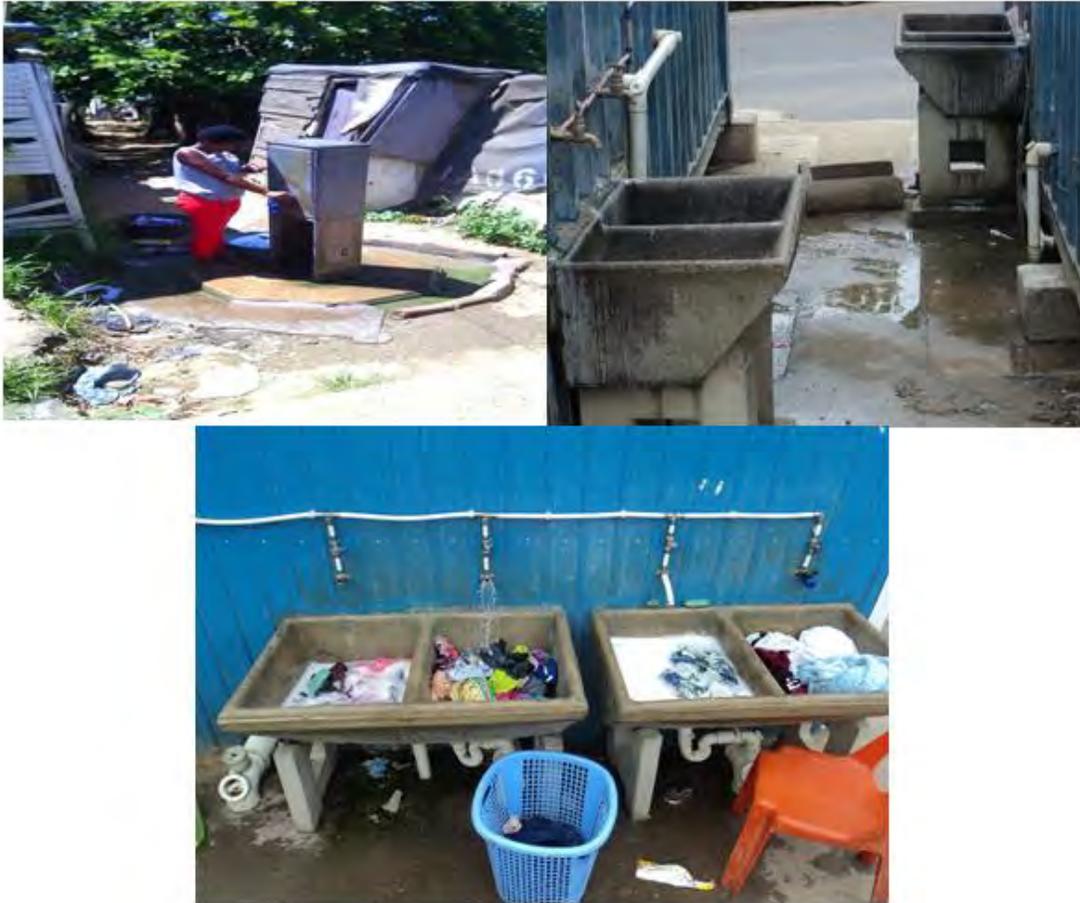


Figure 4.3: Areas surrounding communal taps

A common complaint among CHWs was that it is the norm to find water leaking around communal taps as shown in Figure 4.3. The communal tap sometime leaks, resulting in stagnant water, which creates breeding conditions for water-related diseases and mosquitos that cause Malaria. Consequently, the communal tap and the area surrounding it could become a breeding ground for infectious diseases. Bacteria can easily be transmitted from the surroundings into the water while people are fetching water. PLWHA can easily contract diarrhea from drinking this water due to their compromised immune systems. In addition family members of PLWHAs, especially children and the elderly face a similar risk of contracting diarrhea and other water-borne diseases.

Poor water quality

Not only was it reported that the area around the taps was dirty, but it was noted that water from the communal taps was not always clean. CHWs reported that sometimes when they fetched water from communal taps, the water was whitish in color and when it was left to settle dirt collected at the bottom of the container.

“Sometimes you find that the standpipe water itself is dirty, you can see at the bottom of the bucket that there is mud.” (Focus Group 1)

CHWs explained that poor quality water is not good for their patients because some have sores and skin rashes; bathing them with dirty water makes the condition worse.

“When the water is dirty sometimes and the patient is suffering from a rash, it becomes an issue for the patient to be bathed with dirty water when their skin is already in a bad state and just makes everything worse.” (Focus Group 1)

The unavailability of water results in patients having to store water for long periods of time. Since PLWHAs have a weak immune system, poor water quality and poor water storage pose the risk of opportunistic infections which affects the wellbeing of patients and their family members. It became apparent in the focus group discussions that many people did not store their water in clean buckets or containers (Figure 4.4).



Figure 4.4: How some households with PLWHA stored their water

Poor storage caused the water to taste bad:

“Sometimes the patients keep the water for too long that it actually starts tasting bitter and appears undrinkable and they drink it still and you find that it’s starting to turn green and they still drink it like that., It’s sad, because you want them to get fresh water but because of the situation you are unable to.” (Focus Group 5)

It became apparent in the focus group discussions that poor quality water had ramifications for PLWHA. Patients ended up not taking their medication at the appropriate time either because the water that was available was not clean or because there was no water at all. In some communities, the municipality provides a limited amount of water, for example, 100L a day for the entire household. However, because there are other people in the household the water is finished early in the morning. For example, children bath in the morning before going to school and the water runs out. This leaves the patient with no water during the course of the day to take their medication or bath. This has implications for patients’ well-being because when they do not adhere to their prescribed TB medication and/or ARVs they can become resistant to the drugs and the drugs stop working. The result is that the patient gets sicker and their health cannot be stabilized.

“The patient might need to take pills (ARVs), let’s say at 8 o’clock and they miss the time because there is no more water. The measured water is finished because children bathed with it before going to school and they finished all of it.” (Focus Group 1)

CHWs explained that when a patient is prescribed TB and/or HIV treatment they experience side effects such as diarrhea and vomiting as the body adjusts to the medication. They therefore emphasized the importance of clean water to bath patients as well as for them to take their medication. Unclean water puts the patients at risk of contracting diarrhea which reduces the rate of absorption of ARVs.

“Sometimes when the patient starts the treatment for HIV and Tuberculosis, the medication usually have complications in the initial stages. The patient experiences stomach aches, diarrhea, they vomit... So water is very important. If the patient has unclean water that becomes a huge problem because the patient is unable to clean after themselves properly which exposes them to more bacteria in the home and puts them at risk of contracting opportunistic infections.” (Focus Group 1)

Were water to be readily available in HBC, caring for PLWHAs would be much easier CHWs would be able to spend more time with their patients as time would not be lost fetching water. Patients would be able to take their medication at the prescribed time, thus increasing adherence to treatment. They would also be able to have proper baths. All these factors would improve the quality of life of PLWHA.

4.3 Sanitation and hygiene

4.3.1 Conditions of homes and toilets

Some patients suffering from AIDS and/or TB or diabetes live alone and depend on CHWs to bath them, change their diapers and clean up after them. CHWs only visit their clients once a week. Consequently, it is typical for a CHW to arrive at the patient's home and find the house locked with all the windows closed, with the patient having soiled themselves with feces and urine. Different houses exist in these communities (Figure 4.5). RDP houses are provided by the current government, while what are called four room houses were built by the apartheid government. Finally, there are tin houses or shacks made out of planks. Most of the tin houses and shacks have no windows, just a door into one room where the occupants do everything.



Figure 4.5: Different types of houses found in informal settlements

Some bedridden patients live alone in one room houses. A bucket is usually placed next to the bed and the patient places used diapers in the bucket. Due to the bad odors emanating from the bucket, the patient sometimes asks for it to be placed a bit further from the bed. However, sometimes the patient is too weak to walk to the bucket. Hence, he/she attempts to throw the diaper in the bucket

from the bed. When the attempt fails, the feces splatter on the floor and the bed. The bucket is only removed when the CHW visits the patients' home once a week. If the CHW does not make it to the house that week, the nappies will remain in that state until he/she visits. CHWs reported that they find these rooms in appalling condition, with a very bad smell, and they are the ones that have to go in, open the door for some fresh air and clean up.

“Sometimes when you get to the patient whom you only see once a week you may find that in their room there is a plastic bag heaped with disposable nappies, hanging for days in the same room as the patient. When you enter the patient's room you are greeted with a bad smell, the kind of smell that makes you dizzy.” (Focus Group 2)

Patients are isolated and because they are weak, they are not able to maintain proper sanitation and hygiene in their immediate environment.

CHWs reported that patients suffering from AIDS experience a loss of appetite. Sometimes, when they are offered super, they are unable to eat it and food is left overnight beside the bed. CHWs have to clean up dried food on plates infested with ants and cockroaches. Rotten food also contributes to bad odors.

“When we arrive there in the morning we find dirty dishes with maas (sour milk) is dried up and there is ants and the whole place smelling bad.” (Focus Group 3)

Moreover, the majority of community members used pit-latrines that were in poor condition with no proper door, fly screen or a roof (Figure 4.6).



Figure 4.6: The unfavorable conditions of some of the pit-latrines

Unfavorable conditions in the homes are exacerbated by where the toilets are placed or positioned on the premises. Some of the pit-latrines are constructed right next to the house such that they can be smelt in the house. They also attract flies. As a result the doors and windows to the house are kept closed. This has implications for patients that need fresh air. Family members are also affected because they live in closed spaces with an AIDS patient and since many PLWHA are co-infected with TB, family members are at risk of contracting this disease.

“You find that you cannot even open the window since it is right next to the toilet and the flies will just swarm in. So you have to constantly keep the windows closed or, when you open the door you don’t open it wide enough for fresh air to circulate because you are trying to keep these disease-bearing flies from coming in. So there’s always that stuffiness in the house and even in the bedroom the patient is sleeping in. Even if it is neatly organized but there’s just that stuffiness.” (Focus Group 1)

In some instances family members move their sick relative into a room in the backyard. The patient therefore has no access to the toilet and sometimes has to wait for one to be dug. However, due to limited space in the yard and overcrowding in the community, this may take some time. The patient is forced to defecate in open spaces such as nearby bushes or in the backyard where garbage is disposed of.

“Sometimes you find that a person has been placed in that house because he or she is not well but there is no toilet [hooting minibus taxi interrupts in the background] and that person is still

waiting for a pit toilet to be dug up. In these circumstances you may find them compelled to use a pit where garbage is disposed of and burnt.” (Focus Group 2)

Some households that did not have toilets were using plastic container toilets supplied by the municipality. These toilets are placed in central places like the communal taps discussed above. PLWHAs reported to the researcher during observations that they faced challenges in accessing the toilets at night because they are far from their homes and it is not safe for them to walk around at night. As a result they used a bucket at night and disposed of the waste on the street close to their house in the morning (Figure 4.7).



Figure 4.7: Fecal matter and urine discarded on the roadside due to a lack of toilets

The disposal of fecal matter and urine causes bad odors around homes. During the home visits, household members complained that some days the bad odors emanating from the street were so strong that they had to keep all the windows closed.

CHWs also reported a lack of ventilation in the households of PLWHA which contributed to unhygienic conditions.

“There is a home I once went to and there was no window, just a cardboard placed there and the only time they get exposed to fresh air is when the door is open.” (Focus Group 4)

Another participant added:

“In some instances you find the house clean and air is flowing, but because someone has an issue with a septic sore then you can smell it as you enter the house.” (Focus Group 4)

4.3.2 Inadequate water to clean homes and toilets

CHWs stressed the importance of water in community-based care to improve the living conditions of PLWHA as well as their family members. If water is available, homes can be easily cleaned resulting in fewer bad odors. It is imperative that HIV/AIDS patients be cleaned with water to prevent bacteria from breeding. When there is only a limited amount of water, family members, especially children and the elderly risk contracting diseases that breed in unhygienic conditions.

It was clear that the unavailability of water contributed to a lack of cleanliness in homes. The limited amount of water meant that soiled linen and homes could not be washed or cleaned regularly.

“Uncleanliness is always accompanied by a bad smell, because it’s usually unclean stuff, dirty blankets, there is a bad smell and that is due to them (primary caregivers) not washing the patient’s bed linen. You find that they will feed her (the patient) and leave the dishes there, the dishes are not washed and you can just tell that there is no cleanliness in the home.” (Focus Group 1)

Another participant added:

“It’s different for every household, sometimes you’d arrive and find a sense of cleanliness but in other houses it doesn’t exist. And houses are not cleaned; patients are not washed because there is no water.” (Focus group 4)

As a result of the limited water supply, some households could not be cleaned properly. Some family members reported that they did not clean their homes with water but just swept with a broom. When I accompanied CHWs on home visits an HIV-positive woman reported that the communal taps were far from her home and she found it hard to go there every day. Instead, she fetched water from her neighbor who charged her for the service. She reported that she used as little water as possible to clean her house and sometimes used none at all because she could not afford to pay for water.

Toilets were also not cleaned with water; since most people could not afford to pay water bills, they did not see it as wise to spend money on water to clean toilets. This resulted in bad odors. While some families used detergents to get rid of the smell, most could not afford to do so and the toilets remained dirty, attracting flies that invaded homes.

“The ones (toilets) on the outside have greater problems, because there is no space; when it is full you cannot move and so the flies that carry dirt come to the house, since it is summer, even if you cover the food the flies will come in numbers, so there is no cleanliness.” (Focus Group 1)

Furthermore, some households have built their pit-latrines far from the house and AIDS patients that are weak can't access them. This poses a challenge for CHWs who have to carry the patient to and from the toilet. CHWs improvise by using a “*Powa*” (a container of some sort or a bucket for the patient to relieve themselves). However, a “*Powa*” poses the risk of infection. It also has implications for CHWs because they need water to wash their hands when they handle the “*Powa*” and to wash it properly after they have disposed of the content. CHWs also need protective equipment such as gloves to handle the “*Powa*”. They reported that they rarely have all the necessary material, making it hard for them to practice hygiene in home-based care.

“If you see that the patient is too weak, you ask them to relieve themselves in the house, we ask the patient to use a “powa” (bucket), so we go and help them (patient), cover it (feces) and go out with it (dispose of it), go back to help them, put on gloves and clean them up. Sometimes depending on how weak they are, we use diapers.” (Focus Group 5)

With regard to households whose toilets are located far from the house, CHWs explained that AIDS patients have difficulty controlling their bowel movements. Because they are weak, they walk slowly and end up defecating in their underwear before they reach the toilet. The CHWs reported that this happens often and they feel bad because they are not always able to be there when the patients need them. Sometimes CHWs are delayed at other homes as a result of the WASH challenges faced in the community. When patients urinate and defecate in their clothes they tend to develop skin rashes and sores. This means that the CHW will have to spend more time with the patient to care for their needs. The more time the CHW dedicates to the patient the longer it takes for them to reach the next house.

“You see, if the toilets are outside it is difficult to walk and reach outside, some stay with young kids and the children cannot carry the person and we too as care givers have many homes to visit. If we are unable to get to the home so the patients end up spoiling themselves. This may lead them to developing sores and rash... ” (Focus Group 1)

As noted earlier, the South African government is in the process of providing houses for the community through the RDP. While some of these houses have toilets, the unreliable water supply poses a challenge to keeping them clean. Moreover, while complete, some RDP houses have no water connection because people move in out of desperation before the water is connected. In order to save water, household members use the toilet without flushing. For example they would urinate in the toilet and would not flush; the only time that they would flush is when somebody empties their bowels. Water that is set aside to flush the toilet is dirty water that an individual keeps after having a dry bath; this is very common in peri-urban communities. Sometimes people forego bathing and if that happens, there is no water to flush the toilet.

“.....you'd find that upon arrival at that house the toilet isn't flushed.” (Focus Group 4)

Another participant added:

“Yes toilets are not flushed; there is no water.” (Focus Group 4)

It was also reported that toilets are not provided in RDP houses. A small room is built that is meant to be the bathroom and it's up to the owners to build a toilet. It was reported that most people did not have the means to install a toilet so they dig a pit latrine and while they wait to find space for it they use open spaces to defecate.

The fact that patients have to walk long distances to reach toilets or that toilets are built too close to homes, causing bad odors, does not bode well for their wellbeing, prolongs the healing process and violates their dignity.

4.3.3 Waste Management

As noted earlier, clinical waste is sometimes dumped on the street. The CHWs also reported that clinical waste from patients is not separated from household waste. They themselves dispose of clinical waste from their patients such as used diapers, gauze and swabs in the same plastic waste bag provided by municipality for household waste (Figure 4.8). Although they are advised to burn the waste and would prefer to do so, time was cited as a major problem.

“We clean bed-ridden patients' wounds and bed sores and throw the gauzes and swabs in the same plastic bags where we throw all the waste from the house. We are advised to burn the waste

and we prefer to burn it, however, we often do not have the time so we resort to just throwing diapers, gauzes and swabs in household bins.” (Focus Group 2)

This compromises infection control in HBC as it was reported that children played with rubbish bins that contained sputum and other bodily fluids from patients. This exposes children to infectious diseases such as TB and they are also more likely to develop diarrhea.

In some communities, the municipality provides households with garbage bags, which are collected once a week. The CHWs felt that the municipality should provide more plastic bags for waste disposal, especially to households with AIDS patients. They complained that one rubbish bag per week is not sufficient. The bag fills up quicker in households with AIDS patients and children because of the many diapers that need to be changed. Bags are overfull, resulting in spillage. People also tend to throw dirt around the plastic bag when it fills up.

“We encounter rubbish spilling out in the yard, the other issue is that if we have a sick person who uses diapers, and a child who uses diapers, we have an issue because municipality only gives us one rubbish packet a week, that one packet will be used for all these diapers, and the rubbish bag fills up quickly; next rubbish is thrown anyhow.” (Focus Group 1)

A participant in another focus group added:

“Here in We receive the bin bags only once and after they run out it is your own problem. And it happens sometimes that when those bin bags are delivered they are thrown into the yards while there is no one home. The passer-by comes along and takes it for themselves and one is left with no bin bags. Sometimes they (plastics) just don't get delivered, period.” (Focus Group 2)

The municipality collects the garbage once a week on a specific day; for example, a Tuesday. All households need to take out their garbage bags in the morning and place them on the roadside. However, when the plastic bags are left outside overnight for collection the following morning, animals are attracted to the rubbish. During the night, dogs scavenge the waste and it is left scattered around the community. This waste is not only household waste but waste from AIDS patients.

“When dogs arrive at night they scatter the garbage and the wind comes and blows your entire neighbor's filth to your premises!” (Focus Group 2)

The CHWs expressed concern that garbage is sometimes scattered all over the yard, from the patient’s gate all the way to their door. This usually happens when municipal workers are on strike. Sometimes household members do not take their garbage bags out on time and miss the truck. In such cases, the garbage is left on the streets for the entire week until the next collection.



Figure 4.8: Household garbage mixed with clinical waste left on the open street

The CHWs have developed different strategies to reduce the amount of clinical waste in the environment and the risk of infection. One strategy is to find ways of storing garbage where it cannot be easily reached by animals while another is to only place the garbage on the roadside on the day of collection.

“In one of the households I work, the lady would throw waste from the patient in a plastic bag, tie a knot, and put it in a bin outside, but when I would come in I would find the plastic torn by the dogs, and so I told her that the better thing to do is to place plastic with waste from the patient in a higher place like a tree where the dogs cannot reach the bag, and only remove them when the DSW truck comes to collect dirt.” (Focus Group 4)

4.3.4 Hygiene practice in home-based care

Community caregivers come into contact with the bodily fluids of PLWHAs in their day-to-day activities. They have to clean patients’ sores, bath the patient, change their diapers, wash soiled linen, and empty buckets containing feces, clean vomit, etc. The CHWs need to wear protective equipment such as gloves, aprons and masks when they come into contact with HIV/AIDS/TB patients.

“While wearing gloves you take the excrement, you take the “powa” containing those (feces) and empty it out in the toilet.” (Focus Group 2)

It is clear that CHWs need protective equipment to protect themselves from HIV and TB infection, and other bacteria causing diseases as they perform their jobs. However, since CBOs depend on donors for funding, they do not always have the money to buy equipment. They also depend on government and the Department of Health to supply them with material. It was noted during the interviews that HBC organizations do not have money set aside to buy protective equipment. CHWs were concerned that they do not always have protective equipment and sometimes go for months without it. The supply of material from the Department of Health is inconsistent and CHWs do not always receive materials on time, forcing them to go into the field without it.

“They supply us with equipment in bulk but these only last us for three months or so and then we don’t have protective equipment for the following three months...” (Focus Group 4)

CHWs stated that they hardly ever have a full HBC kit; there is always something missing:

“Yes we do get access to gloves and we use them. But there are some things that are still missing. For example when we are going to see someone with TB, we just go as we are without masks and this puts us at risk of contracting TB.” (Focus Group 2)

Because of limited resources, CHWs end up reusing gloves. Once they have finished bathing the patient and performing all the necessary activities, they rinse them with water and use the same pair of gloves on another patient. As noted earlier, water is scarce in these communities, so they use very little water to rinse the gloves. The CHWs reported that their gloves would sometimes tear as they were putting them on or while performing their duties. As a result, they refrain from performing certain activities for fear of contracting HIV. This has implications for the patient and in turn creates a burden for family members that are left without the assistance of CHWs. However, CHWs sometimes work with poor quality material or no material (Figure 4.9) because they feel bad about leaving the patient without care though they reported that they felt very uneasy when they did so.



Figure 4.9: This CHW's gloves were torn and she was forced to attend to the patient without gloves

During home visits it was not unusual to see CHWs attending to clients without facial masks. Facial masks were the least used equipment, as they were more likely to be unavailable than gloves. It could be argued that CHWs almost always had gloves because they were reusing them. Instead of using a mask, they reported that when the situation was really bad they would cover their mouth and nose with a cloth and tie it behind their head but this was very rare. They usually attended to patients without covering their mouth and nose.

One of the project managers stated that they are asked to order equipment from the Department of Health once a year. When the masks are finished, they can't order only masks, but have to wait until all the equipment has been used and then place an order. Consequently if one piece of equipment is finished, CHWs have to do without it. Hence CHWs are at risk of contracting HIV or TB. It was clear during the focus group discussions that they were well aware of this risk:

"We usually go to the people who are infected with TB, even if we do not have protective material, but the organization help us by going to check us up for TB regularly." (Focus Group 4)

In another focus group a CHW added:

"We are taught that it is important to open windows when you arrive in the morning so that fresh air can circulate so that even if I arrive as a caregiver and there is sickness I would not contract the sickness easily, but it does not happen that way because I'm the one that goes in the stuffed

room to open the windows without a mask and I'm continuously exposed to individuals who are infected with TB.” (Focus Group 1)

There is a need for protective equipment as well water to maintain hygiene in HBC. The unavailability of water makes it hard for CHWs to maintain hygiene and they end up leaving the patient without cleaning them. This makes CHWs feel really bad. Moreover, patients that are not bathed have a lower quality of life.

‘Sometimes you find that the patient you are looking after has soiled themselves and you would need to help get them clean. It is difficult to leave a patient who has soiled themselves without giving them a bath because we were not able to access water.’ (Focus Group 4)

CHWs need water to maintain hygiene as they move from house to house and patient to patient for infection control purposes. They need to wash their hands thoroughly with soap to protect themselves as well as to prevent transmission of diseases from one patient to another.

...”It is important for us to wash our hands when we are done so that we do not easily contract the sickness.” (Focus Group 1)

The CHWs were also aware that even though they have difficulties accessing water, it is important in reduce the risk of transmission. They need water to wash their hands and to perform a thorough job, i.e., bathing their patients and cleaning their homes:

“The water also helps us, as people who are there to help the patients, as it helps us stay clean by washing our hands, bathing, keeping clean.” (Focus Group 4)

Maintaining hygiene in households with PLWHA is a challenge because many patients need diapers. However, most cannot afford them and rely on the Department of Health. The CHWs reported that diapers are not supplied on time and the patients end up using sheets as diapers which is unhygienic and puts them at risk of contracting opportunistic diseases. The use of sheets also adds to the problem of hygiene because CHWs and family members have to wash and reuse them, unlike disposable diapers. Given limited water resources, this may result in soiled sheets being kept in the house for days until family members or CHWs fetch enough water to wash them.

“Sometimes you find that these AIDS patient are in need of disposable nappies but cannot afford to buy them. Though at times we do ask for nappies from the Department of Health, the DoH delays in delivering the disposable nappies. So you find that during that time our patients have to wait and use sheets in the meantime. The scarcity of nappies contributes to unhygienic conditions and makes it difficult for the family to take care of the patient.” (Focus Group 1)

In addition, it was found during the interviews and home visits that some family members were not very keen to care for their loved ones and left the job to CHWs. Even though some patients lived with family members, most of their relatives did little or nothing to maintain cleanliness in the home. This was left to the CHWs even though they only visited once a week.

“They (Patient) do have a family but the family doesn’t want to take care of them. And the people they live with at home do not clean after the patient.” (Focus Group 2)

It is also the case that some family members do not want to care for patients because of the amount of work involved and because such work is perceived of as risky and disgusting. The unavailability of water adds to the burden of care.

In conclusion, clean water, proper sanitation and hygiene are very important factors that contribute to the wellbeing of patients living with HIV/AIDS/TB, their family members and CHWs. The three WASH factors are interrelated and intertwined. Water is necessary for sanitation and is also needed to maintain hygiene. In light of the conditions highlighted above, it is imperative that water and sanitation are delivered hand-in-hand with hygiene education in order to improve the quality of life and well-being of patients, family members and CHWs. Inadequate access to water influences sanitation and hygiene and this affects the work of CHWs. The diagram below illustrates the relationship between the three components.

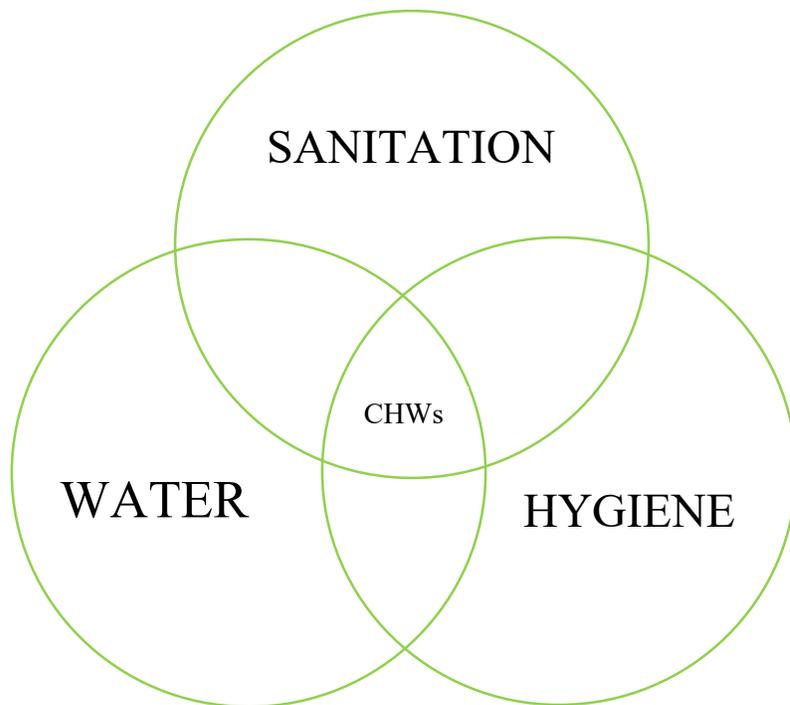


Figure 4.10: The relationship between water, sanitation and hygiene and CHWs

CHAPTER FIVE

DISCUSSION OF FINDINGS

5.1 Access to water in community and home-based care

The study's findings show that people living in informal settlements are the most affected when it comes to WASH issues. Most community members rely on communal taps for water. This finding supports Manase et al. (2009) and Ngwenya and Kgathi (2006) who reported that 84% and 73% of their respondents fetched water from communal standpipes and only 6% and 4.8% had piped water inside their homes, respectively. However a number of communal taps were damaged and had not been fixed by the municipality. Brieger et al. (1997) acknowledge that local residents have found it difficult to maintain and operate hand pipes even though these pipes can be easily fixed with hand tools. The current study found that the distance between the taps had increased. In most cases, it was reported that only one tap was working in a section (area) instead of the four that are usually provided by the municipality. This has resulted in community members having to walk long distances to access water. The CHWs reported that they had to travel to neighboring areas (sections) as a result of the unavailability in some areas. Ngwenya and Kgathi's (2006) study on HIV/AIDS HBC in rural communities in Botswana also found that village residents would travel to surrounding villages in search of water.

At the micro-level, a PLWHA is not able to access water as they are bedridden or too weak to walk. They therefore rely on others to fetch water for them. Thus, at the meso-level, family members of PLWHA are expected to fetch water for patients. While family members, also referred to as primary caregivers, have the primary responsibility of taking care of their loved ones, they face other pressing demands such as providing for the family financially. Moreover, primary caregivers are forced to walk long distances in the early hours of the morning to access water for patients as well as for the household. Most households with PLWHA also have children and they require water to bath before going to school. This also has an impact on the patient because the water often runs out in the morning before the patient gets to use it. To tackle this problem, the community and the government could work together to raise funds to install boreholes on every household's premises. These could be used to access water during periods when it is scarce.

Furthermore, family members are only able to fetch limited amounts of water due to time constraints as they have to go to work. Kamminga and Wegelin-Schuringa's (2003) study showed that water collection in AIDS care reduced the time available for other activities. Those caring for AIDS patients had less time to get involved in other activities such as taking part in community meetings/forums to improve their community. Hence, WASH issues may end up not being resolved in low-income communities because people don't have time to discuss how to resolve such issues. When the communal tap is some distance away, the primary caregiver can only make one trip and the water collected is usually not enough to last the whole day for the entire household. In some of the households we visited, the amount of water available did not meet the WHO or DWAF standard of 25L/capita/day (WHO, 2008; DWAF, 2008). The government could address this problem by employing local plumbers to oversee the communal standpipes and fix them when there is a breakage. The failure of primary caregivers to provide water for patients results in this responsibility falling on the shoulders of CHWs (exo-level).

The issue of illegal water connections was a major concern when it came to access to water in informal settlements. The study found that illegal connections were a common practice in these low-income communities. Manase et al. (2009) found that the majority of yard taps were illegally connected to the main line installed by the DWAF which is meant to supply water to the communal taps. Illegal water connections resulted in less water being available in the community especially over weekends when most people are at home. They reduce the water pressure at the communal tap, resulting in more time being spent to fetch water. This has implications at community level as CHWs spend more time fetching water and little or no time is left to spend with patients.

During weekends, there is high water demand and overcrowding at the communal taps. The water pressure drops, resulting in long queues and delays. Households have learnt to take turns. When one household finishes using water, for example, washing laundry, and closes the tap, the next household can open their tap. However, due to high demand on the communal tap and illegal connections, little water flows from household taps. This negatively affects the care of AIDS patients whose water needs are very high and are crucial to their health and wellbeing. Research shows that households with AIDS patients use more water than those with no PLWHA (Ngwenya & Kgathi 2006; Potgieter, 2007; Potgieter & du Preez 2012); therefore, waiting for other households to be done with water affects those with PLWHA who need large quantities of water.

Thus, the municipality should educate community members about illegal water connections, since many people who had illegal connections did not know that what they were doing was against the law. Sanctions can be imposed on people engaging in this kind of behavior such as paying a fine.

Illegal connections also contribute to the poor quality of water. When the pipes are not connected or installed properly from the standpipe, dirt penetrates them and affects the quality of the water. Furthermore, CHWs reported that the quality of water from the standpipe is generally poor; they described it as being whitish in color and they sometimes found residue at the bottom of the container or bucket. This has implications at the micro-level (PLWHA), as patients are at risk of contracting opportunistic infections as a result of their compromised immune system. Children and the elderly are also at risk.

Households that have running water in their yards and homes also confront challenges with regard to water. The water supply is unreliable and the municipality often delivers water using a tanker. This poses a challenge because not everyone is able to access the truck as it does not deliver door-to-door. People have to walk to where it is parked. Furthermore, not everyone is available at the time the truck is parked in the area. For example, family members of PLWHA may still be at work and patients themselves may not have the strength to walk to the truck to fetch water at a specific time.

In addition to unreliable water sources and challenges in accessing water, the areas around the taps were visibly unhygienic. Moreover, almost all communal water sources leaked. As a result the areas were muddy and had stagnant water (Figure 4.3 in chapter 4). These leakages contribute to water shortages in these communities. Thus, as much as there was a shortage of water, there was also wastage due to leakages. Some taps had been leaking for years, to the point of damaging roads. Wasted and unaccounted for water has implications at community level (exo-level). The community suffers recurrent water shortages which has implications for the health status of community members. People are unable to maintain hygiene. Moreover, the clinics in the community need water to operate effectively. Health professionals need to wash their hands properly as they attend to patients. These communities are also served by social workers who go door-to-door conducting HIV/AIDS testing. They need water to wash their hands but, due to water shortages, they are forced to carry their own water when they conduct home visits. Thus, the government needs to address the issue of water leakages especially now that Durban in general is

facing challenges with regard to a shortage of water. The community needs to mobilize to bring government's attention to the need to repair broken pipes and poor connections that are causing leakages that are so bad they are now destroying the roads.

5.2 Conditions of homes and toilets in community and home-based care

The study found that the homes occupied by PLWHA and their toilets they used were not in a suitable condition. The participants reported that homes smelt appalling and were not properly cleaned due to water shortages. They also reused waste water. For example, after the CHWs finished bathing a patient, they would use the waste water to clean the house or keep it to be used to flush the toilet. This finding is similar to what Ngwenya and Kgathi (2006) found in Botswana; they referred to the reuse of waste water as "economizing water".

The reasons for such appalling conditions are that, firstly, PLWHA are unable to clean and take care of their home environment due to illness. A study conducted several years ago on the dynamics of guinea worm infection among women in Nigeria found that these women were unable to perform household duties to keep their home environment clean and hygienic (Yacoob et al., 1989). Patients who are bedridden are unable to perform daily household duties; this results in appalling living conditions. Such patients can easily contract opportunistic diseases such as diarrhea. Limited access to water added to the appalling conditions of households in HBC. Homes cannot be cleaned properly and soiled linen cannot be washed regularly and is kept in the room where it causes bad odors, especially during summer. Consequently, the availability of water is crucial for both maintaining a certain level of hygiene in the home as well as reducing the risk of infection from contaminated water.

In addition to the implications stated above, PLWHA's appalling living conditions affect their healing process as well as their general wellbeing. For example, neighbors and friends avoid visiting such homes and the patient becomes isolated (Ngwenya & Kgathi, 2006). This study found that the only people that visited some patients were the caregivers. Family members need to become more involved in caring for HIV/AIDS patients, although this may not be possible in every household simply because not every household has people available to care for the patient. However, where people are available, intervention is required. For example, CBOs could mobilize family members to help the patient as much as they can.

Secondly, some patients are living in unhygienic conditions because family members have neglected them due to their illness. It is common in these communities for a patient to be placed in an isolated room behind the house. One of the reasons for doing so is to reduce contact between the patient and family members. However this has severe implications for the patients. Firstly it isolates the patient, who is likely to feel lonely and become depressed. Secondly, reduced contact between the patient and family members means that the patient's needs are not continuously catered for. They are not bathed or fed regularly and their room is not cleaned regularly. Such an environment is not conducive for the patient's overall well-being and also puts them at risk of contracting opportunistic diseases. It also poses a risk to family members when they decide to visit the patient, as they can easily transmit bacteria from the patient's room into the main house. The CHWs are also at risk. Limited access to water increases the rate at which infection is spread since there is not enough water to wash their hands, and linen etc. This study found that CHWs were at risk of contracting TB in HBC. This finding is similar to that of Akintola and Hangulu (2014) who also found that CHWs were at risk of contracting opportunistic diseases such as TB.

While the study found that there were different types of toilets in these communities, most community members used pit-latrines. Many have dug such latrines in their back yards, while others use communal ablution blocks provided by the government. Due to limited resources, many households do not have the capacity to build flush toilets and cannot afford to pay water bills. This finding supports the literature which notes that there is a lack of access to adequate sanitation facilities in sub-Saharan Africa (WHO & UNICEF, 2010) due to weak infrastructure and a lack of resources (WHO, 2011; Yallew et al., 2012). The current study found that some pit-latrines were built very close to homes. These toilets were shallow and were not built according government guidelines and regulations. They did not have fly screens, proper doors, a roof or ventilation (Figure 4.6). This finding is similar to that of Potgieter et al.'s (2007) study in Limpopo that found that pit-latrines were shallow and did not comply with government regulations. This contributed to unhygienic environments for patients and their families. Thus, the government should closely monitor pit-latrines in these communities. Owners of those that are not up to standard should be required to upgrade them with government assistance.

Furthermore, it was found that the toilets were not cleaned because some people didn't see the need to do so. Some community members felt that cleaning the toilet with water wasted water,

considering the trouble they had to go to, to fetch water. Some community members buy a certain detergent with a strong scent which is sprinkled in the toilet to get rid of the bad odor. However, not all household can afford detergents. Most leave the toilet as is. Due to the poor structure and unhygienic conditions of the toilets, some community members prefer to practice open defecation in the nearby open bush or places near the river. This practice was most common during the rainy season when the pit-latrines were regarded as unsafe. According to the WHO (2011) and Yallem et al. (2012), a lack of sanitation facilities leaves people with limited options, with individuals forced to defecate in open spaces or in a river as well as in areas close to where children play. Open defecation leads to contamination of the soil and people who walk barefoot could become infested with intestinal worms (Wisner & Adams, 2002). The unhygienic conditions of the toilets and open defecation mean that people are more vulnerable to catching water-borne diseases.

Diseases can easily be transmitted by the flies that surround the toilets or by people given the fact that there is limited water to wash their hands after using the toilet. This has implications for PLWHA who are more likely to contract water-borne diseases as a result of their weak immune system. The CHWs and primary caregivers are also at risk of contracting diarrhea from handling the patient's feces.

5.3 Waste management and hygiene practice in community and home-based care

With regard to clinical waste, CHWs were conscious of the fact that the clinical waste from their patients was toxic and harmful to people (themselves, primary caregivers and patients) and the environment. However the South African Department of Health has not formulated a policy to guide the removal of clinical waste in community and home-based care. This is only done in hospital settings, where waste is separated and disposed of in different color-coded containers based on the level of toxicity.

In line with Akintola and Hangulu's (2014) findings, this study found that, unlike in hospitals, in HBC, clinical waste was sometimes not separated from household waste. All the waste from the household, including clinical waste was placed in one black or orange garbage bag provided by the municipality and placed on the roadside for collection once a week (Figure 4.8 in chapter 4).

This means that members of the family have prolonged exposure to harmful waste while it is in the home or the environment surrounding the home. The fact that CHWs wrap clinical waste and discard it in the proximity of patients, themselves and members of the community raises the challenge of waste management in HBC. Kang'ethe's (2008) study also reported inefficiencies in managing clinical waste and maintaining decent sanitation and hygiene in HBC.

CHWs have come up with strategies to deal with patients' waste. To minimize the public's exposure to such waste, CHWs dispose of it in pit-latrines. However, this exposes them to bacteria from their patients. Secondly, pit-latrines are not an appropriate place to dispose of clinical waste. The waste accumulates in the toilet and other members of the household and community members who share the pit-latrine risk infection.

Moreover, the study found that CHWs performed their duties without a comprehensive set of protective material. A comprehensive HBC kit would consist of a set of gloves, a mask, an apron, bandages and disinfectant. One of the reasons why CHWs often work without a complete set of protective material is that HBC organizations rely on international donors and the government for funding (Johnson & Khana, 2004; Rodlach, 2009). This funding is sometimes delayed and some organizations receive limited funds. Akintola, Gwelo, Labonte and Appadu (2015) found that the global financial crisis affected the resources and funding made available to non-profit organizations such as those involved in HBC. This has affected the availability of HBC materials as there are limited funds to purchase them. Similarly, Akintola and Hangulu (2014) found that CHWs had limited access to protective equipment in HBC. Due to the high prevalence of HIV in South Africa there is high demand for HBC kits that has exceeded availability and supply (Mabude, Beksinska, Ramkisson, Woods & Folsom, 2008).

The CHWs stated that they reuse gloves. Kang'ethe (2008) found that approximately half of the caregiving material required by CHWs was missing in HBC. The current study found that masks were most scarce. The lack of protective equipment exposes CHWs to the risk of contracting HIV, TB and other infectious diseases. The study found that the CHWs perceived themselves as being at risk of contracting HIV and TB. They reported that they sometimes refrained from performing their duties if they did not have gloves for fear of infection.

This has implications at the micro-level (PLWHA). When CHWs refrain from performing their duties this has strong repercussions for patients who are not cared for. Their already unhygienic

living conditions would worsen which may lead to them contracting opportunistic diseases and could cause premature death.

At the meso-level, family members of patients become overburdened if and when CHWs refrain from performing their duties. This may require that family members have to skip work or take some days off to care for the patient. This increases the levels of poverty that already exist in these communities. Indeed, in some households with PLWHA, one adult is solely responsible for providing for the household's financial needs. Limited access to water hampers the maintenance of proper hygiene and sanitation in PLWHA's households. Thus, the government needs to set aside funding to enable CBOs to buy protective equipment for CHWs. Furthermore, a policy should be adopted that every HBC organization must set aside funding for such equipment.

5.4 Conclusion, recommendations and the limitations of the study

5.4.1 Conclusion

This study explored issues relating to WASH in home and community-based care for PLWHA in peri-urban, low-income communities on the outskirts of Durban, South Africa. It identified the community's water access points and the availability of water in these communities. The study also reported on the state and conditions of homes and toilets of households that CHWs visited to offer care, mainly to PLWHA. Finally, it investigated how clinical waste was managed and reported on hygiene practice in HBC. The ecological systems theory was used to interpret the findings, focusing on its first three levels, namely, the micro-level (PLWHA), meso-level (patients' family members) and the exo-level (CHWs and HBC CBOs), respectively. The study sought to answer three questions:

- What is the current situation in relation to WASH in community and home-based care?
- What challenges do CHWs face with regard to WASH in community and home-based care? How do they cope with these challenges?
- How does WASH affect the general well-being of PLWHA, their family members and CHWs?

A qualitative research design was used to collect data due to its ability to elicit rich, descriptive data from participants. This study sought to gain a deeper understanding of WASH from the perspectives of CHWs, since they have first-hand experience of their patients.

This section synthesizes the empirical findings to answer the study's three research questions.

1. Current status of water, sanitation and hygiene

The majority of households in these communities accessed water from communal stand pipes. The taps were often located some distance from the household and this affected the amount of water available in individual homes. Moreover, community members connected water illegally from the main pipe to supply water to their yards. This had tremendous effects on the standpipes' water pressure, resulting in more time being spent on fetching water. Thus, the study found that these low-income communities had an unreliable water supply, with informal settlements being worst affected. With regards to sanitation the limited amount of water available made it difficult for homes and toilets to be cleaned properly. Hence, many households were reported to have poor hygiene. Finally, the unreliable and limited water supply negatively affected the care of PLWHA.

2. Challenges faced by CHWs with regard to water, sanitation and hygiene

CHWs faced a number of challenges with regard to WASH. The first was the distance they had to walk to access communal standpipes and the time lost fetching water. This resulted in CHWs spending less time with their patients. The CHWs reported not being able to wash soiled linen as a result of limited amounts of water. They also reported giving dry baths and were sometimes unable to bath the patient at all. This happened when there was no water in the household and no one to assist with fetching it. The CHWs also faced challenges in managing clinical waste. They reported that they disposed of such waste in pit-latrines in the backyard and sometimes mixed it with household waste. The mixed garbage is placed on the streets for the municipality to collect. Municipal workers are thus exposed to infectious material. Finally, CHWs reported that they had limited access to protective equipment such as gloves, masks and aprons that would help them perform their duties as well as protect themselves and their patients from infection. The study found that there was a high risk of contracting infectious diseases such as diarrhoea, TB and HIV in HBC.

3. The implications of water, sanitation and hygiene for the general well-being of PLWHA, CHWs and family members of PLWHA

The conditions relating to WASH had implications for the general well-being of patients, CHWs and primary caregivers. Limited access to water and unavailability of water interfered with how

CHWs performed their duties. They refrained from performing their duties (bathing patients, washing soiled linen) when they did not have access to water. They also refrained from bathing the patient when they had no gloves, as they feared being infected. However, they still performed other duties around the house and were thus exposed to risks such as contracting TB. Moreover, limited access to water meant that they were unable to wash their hands properly after attending to the patient's needs. At the micro-level, when the patient is left without taking a bath and bed linen is not washed, they are more at risk of contracting opportunist diseases. Unhygienic conditions would also make it hard for the patient, CHWs and family members to manage the patient's disease and may lead to premature death.

The study's findings have policy implications. It is clear that these issues need to be addressed by policy makers. Moreover, this study has identified that while there are clear policy guidelines on how to handle clinical waste in a hospital setting, there seems to be a gap in policy with regard to how clinical waste should be managed in HBC. Thus, the study's empirical findings demonstrate the current status of WASH in community and home-based care.

5.4.2 Recommendations for future research

Issues around WASH are diverse and multifaceted. In order to formulate realistic policy, there is a need to further explore these issues. Further studies could be conducted on the broader aspect of community needs with regards to WASH. Moreover, the particular WASH needs of PLWHA and patients with other illnesses that require palliative HBC should be examined. Extending the research to the general community, PLWHA, their family members and ward councilors or ward committee members would provide further insight on WASH in low-income communities, especially informal settlements in South Africa to inform policy makers. This study informs us that there is a gap in policy with regards to the collection of clinical waste from HBC. There is a need for policy to guide the collection of clinical waste from the HBC. There also needs to be a better implementation of existing policy for CHWs.

5.4.3 Limitations of the study

The limitations of the study include the fact that this was a qualitative study with a sample of only a few organizations. Therefore, care should be taken in generalizing these findings to other contexts. Furthermore, the sample was obtained using snowball sampling, hence creating room for

bias in that project managers might have suggested organizations that they had a relationship with and/or that operated in a similar manner to them.

5.5 Conclusion

In community and HBC, the provision of safe water, proper sanitation and hygiene to PLWHA is crucial because they are susceptible to opportunistic diseases as a result of a compromised immune system. The subject of WASH is particularly important because it has direct implications for the general health of a population. This study revealed the circumstances and conditions of WASH in four low-income communities in KwaZulu-Natal South Africa and highlighted how WASH affects people in palliative care such PLWHA in the context of HBC. It adds to the body of knowledge on water, sanitation, hygiene and health.

REFERENCES

- Agarwal, A., Kimondo, J., Moreno, G., & Tinker, J. (1981). Water, sanitation, health-for all? *Water, sanitation, health-for all?* Earthcan.
- Aiello, A. E., Coulborn, R. M., Perez, V., & Larson, E. L. (2008). Effect of hand hygiene on infectious disease risk in the community setting: a meta-analysis. *American journal of public health, 98*(8), 1372.
- Akintola, O. (2004). A gendered analysis of the burden of care on family and volunteer caregivers in Uganda and South Africa.
- Akintola, O. (2006). Gendered home-based care in South Africa: more trouble for the troubled. *African Journal of AIDS research, 5*(3), 237-247.
- Akintola, O. (2008). Defying all odds: coping with the challenges of volunteer caregiving for patients with 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, czq019*.
- Akintola, O. (2011). What motivates people to volunteer. *The case of volunteer AIDS*.
- Akintola, O., & Hangu, L. (2014). Infection control in home-based care for people living with HIV/AIDS/TB in South Africa: An exploratory study. *Global public health, 9*(4), 382-393.
- Akintola, O., Gwelo, N. B., Labonté, R., & Appadu, T. (2015). The global financial crisis: experiences of and implications for community-based organizations providing health and social services in South Africa. *Critical Public Health, 1-15*.
- Amoran, O. E., Ogunola, E. O., Salako, A. O., & Alausa, O. O. (2012). HIV/aids related home based care practices among primary health care workers in Ogun state, Nigeria. *BMC health services research, 12*(1), 112.
- Barnett, T., Whiteside, A., & Whiteside, A. (2002). *AIDS in the twenty-first century*: Palgrave.

- Bartram, J., & Cairncross, S. (2010). Hygiene, sanitation, and water: forgotten foundations of health. *PLoS Med*, 7(11), e1000367.
- Baum, F., & Sanders, D. (1995). Can health promotion and primary health care achieve health for all without a return to their more radical agenda? *Health Promotion International*, 10(2), 149-160.
- Bisung, E., & Elliott, S. J. (2014). Toward a social capital based framework for understanding the water-health nexus. *Social Science & Medicine*, 108, 194-200.
- Bisung, E., Elliott, S. J., Abudho, B., Schuster-Wallace, C. J., & Karanja, D. M. (2015). Dreaming of toilets: Using photovoice to explore knowledge, attitudes and practices around water–health linkages in rural Kenya. *Health & place*, 31, 208-215.
- Bjerregaard, P., Berner, J., Oyvind, J., (2008). Environmental and living conditions. In K. Young & P. Bjerredgard (Eds.), *Health Transitions in Arctic populations* (pp. 173-191). University of Toronto press.
- Bjerregaard, P., & Young, K. (2008). Inuit. In K. Young, & P. Bjerregaard (Eds.), *Health Transitions in Arctic Populations* (pp. 119-133). University of Toronto Press.
- Blanche, M. T., Durrheim, K., & Painter, D. (2006). *Research in practice: Applied methods for the social sciences*: Juta and Company Ltd.
- Blinkhoff, P., Bukanga, E., Syamalevwe, B., & Williams, G. (2001). *Under the Mupundu Tree: Volunteers in Home Care for People with HIV/AIDS and TB in Zambia Copperbelt*. London, UK: Strategies for Hope Series No 14, ActionAid.
- Bourne, P.G. (1986). Water and sanitation for all. *Search journal*, 1(4), 41.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Brieger, W. R., Otusanya, S., Adeniyi, J. D., Tijani, J., & Banjoko, M. (1997). Eradicating guinea worm without wells: unrealized hopes of the water decade. *Health policy and planning*, 12(4), 354-362.

- Bronfenbrenner, U. (1979). Contexts of child rearing: Problems and prospects. *American Psychologist*, 34(10), 844.
- Bronfenbrenner, U. (1994). Ecological models of human development. *Readings on the development of children*, 2, 37-43.
- Bryman, A. (2004). Interviewing in qualitative research. *Social research methods*, 2, 318-344.
- Cheng, J. J., Schuster-Wallace, C. J., Watt, S., Newbold, B. K., & Mente, A. (2012). An ecological quantification of the relationships between water, sanitation and infant, child, and maternal mortality. *Environmental Health*, 11(1), 1-8.
- Claquin, P. (1989). *Sustainability of EPI: utopia or survival?*
- Corburn, J., & Hildebrand, C. (2015). Slum Sanitation and the Social Determinants of Women's Health in Nairobi, Kenya. *Journal of Environmental and Public Health*, 2(4), 121-182.
- Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approaches*: Sage publications.
- CSDH (2008). Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health. Geneva, World Health Organization.
- Cueto, M. (2004). The origins of primary health care and selective primary health care. *American journal of public health*, 94(11), 1864-1874.
- Curtis, V., & Cairncross, S. (2003). Effect of washing hands with soap on diarrhoea risk in the community: a systematic review. *The Lancet infectious diseases*, 3(5), 275-281.
- Daley, K., Castleden, H., Jamieson, R., Furgal, C., & Ell, L. (2015). Water systems, sanitation, and public health risks in remote communities: Inuit resident perspectives from the Canadian Arctic. *Social Science & Medicine*, 135, 124-132.
- Davies, M. (2007). *Doing a successful research project: using qualitative or quantitative methods*. Basingstoke [England]; New York: Palgrave Macmillan.
- Davis, P. K. (2009). Financing Home and Community-Based Long-Term Care: Adult Children Caregiver Perspectives. *Graduate Theses and Dissertations*, 530.

- Department of Health. (2001). National guidelines on home based care (Hc) and community based care (Cc). Pretoria, South Africa: National Department of Health.
- DWAF. (2008). Water and Sanitation coverage in South Africa. Department of Water Affairs and Forestry.
- DWAF. (2012). Sanitation services-quality of sanitation services in South Africa, Report. Retrieved from: <http://www.sahrc.org.za/home/21/files/Quality%20of%20sanitation%20-%20Exec%20Summary%20Mar12%20%28Fin%29.pdf>
- Dreibelbis, R., Winch, P. J., Leontsini, E., Hulland, K. R., Ram, P. K., Unicomb, L., & Luby, S. P. (2013). The Integrated Behavioural Model for Water, Sanitation, and Hygiene: a systematic review of behavioural models and a framework for designing and evaluating behaviour change interventions in infrastructure-restricted settings. *BMC public health*, *13*(1), 1015.
- Esrey, S. A., Potash, J. B., Roberts, L., & Shiff, C. (1991). Effects of improved water supply and sanitation on ascariasis, diarrhoea, dracunculiasis, hookworm infection, schistosomiasis, and trachoma. *Bulletin of the World Health organization*, *69*(5), 609.
- Estopinal, C. B., van Dijk, J. H., Sitali, S., Stewart, H., Davidson, M. A., Spurrier, J., & Vermund, S. H. (2012). Availability of volunteer-led home-based care system and baseline factors as predictors of clinical outcomes in HIV-infected patients in Rural Zambia.
- Falkenmark, M. (1982). Rural water supply and health: the need for a new strategy.
- Flick, U. (1988). *An Introduction to qualitative research*. London: Sage.
- Gleick, P. H. (2002). *Dirty-water: Estimated Deaths from Water-related Diseases 2000-2020*: Pacific Institute for Studies in Development, Environment, and Security.
- Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The qualitative report*, *8*(4), 597-606.
- Goldbart, J., & Hustler, D. (2005). Ethnography. *Research methods in the social sciences*, 16-23.
- Guest, G., MacQueen, K.M., & Emily, E.N. (2012). *Applied Thematic Analysis*. Thousand Oaks, CA: Sage.

- Gunnerson, C., Julius, D., & Kalbermatten, J. (1978). Alternative approaches to sanitation technology. *Progress in water technology*, 10(6), 1217-1228.
- Härkönen, U. (2001). The Bronfenbrenner ecological systems theory of human development.
- Hasson, H., & Arnetz, J. E. (2008). Nursing staff competence, work strain, stress and satisfaction in elderly care: a comparison of home-based care and nursing homes. *Journal of clinical nursing*, 17(4), 468-481.
- Henderson, D. A. (1987). Principles and lessons from the smallpox eradication programme. *Bulletin of the World Health organization*, 65(4), 535.
- Hennink, M., Hutter, I., & Bailey, A. (2011). *Qualitative research methods*. Los Angeles: Sage Publications Ltd.
- Heppner, P. P., Wampold, E. B., & Kivlighan, M. D. (2008). *Research design in counselling*. London: Sage Publications Ltd.
- Hopkins, D. R. (1987). Elimination of guinea worm disease. *Contact* 87, 9-14.
- Hudson, P. (2003). Home-based support for palliative care families: challenges and recommendations. *Medical Journal of Australia*, 179(6), S35.
- Hunter, P. R., MacDonald, A. M., & Carter, R. C. (2010). Water supply and health. *PLoS Medicine*, 7(11), 1350.
- Ilegbodu, V., Christensen, B., Wise, R., Ilegbodu, A., & Kale, O. (1987). Source of drinking water supply and transmission of guinea worm disease in Nigeria. *Annals of tropical medicine and parasitology*, 81(6), 713-718.
- Ivens, S. (2008). Does increased water access empower women? *Development*, 51(1), 63-67.
- Jacques, G., & Stegling, C. (2004). HIV/AIDS and Home Based Care in Botswana: Panacea or Perfidy? *Social work in mental health*, 2(2-3), 175-193.
- Johnson, B. A., & Khanna, S. K. (2004). Community health workers and home-based care programs for HIV clients. *Journal of the National Medical Association*, 96(4), 496.
- Jorgensen, D. L. (1989). *Participant observation*: Wiley Online Library.

- Kamminga, E., & Wegelin-Schuringa, M. (2003). HIV/AIDS and water, sanitation and hygiene. *Thematic Overview Paper. Royal Tropical Institute (KIT). IRC International Water and Sanitation Centre.*
- Kang'ethe, S. M. (2006). *Contribution of caregivers in community home based care programmes: The case of Kanye, Botswana.* PhD thesis, North-West University. Retrieved from <http://socialwork.journals.ac.za/pub/article/viewFile/228/211>
- Kang'ethe, S. M. (2008). Clinical waste management in the context of the Kanye community home-based care programme, Botswana. *African Journal of AIDS research*, 7(2), 187-194.
- Kothari, C. R. (2011). *Research methodology: methods and techniques*: New Age International.
- Kumar, R. (2004). *Research methodology: a step-by-step guide for beginners*. London: Sage.
- Lieberson, J., Miller, D., Eckerson, D., & Keller, H. (1987). *An evaluation of the factors of sustainability in the Gambia mass media and health practices project*: US Agency for International Development.
- Ledwaba, L. (2005, December 15) Home-based care a critical need where 1 in 5 have HIV. The New York Amsterdam News.
- Mabude, Z., Beksinska, M., Ramkissoo, 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), 931-937.
- Magnussen, L., Ehiri, J., & Jolly, P. (2004). Comprehensive versus selective primary health care: lessons for global health policy. *Health affairs*, 23(3), 167-176.
- Makaudze, E., Du Preez, M., & Potgieter, N. (2012). *How Does the HIV and AIDS Epidemic in South Africa Impact on Water, Sanitation and Hygiene Sectors?* : Water Research Commission.
- Manase, G., Nkuna, Z., & Ngorima, E. (2009). Using water and sanitation as an entry point to fight poverty and respond to HIV/AIDS: The case of Isulabasha Small Medium Enterprise. *Physics and Chemistry of the Earth, Parts A/B/C*, 34(13), 866-873.
- Mann, J. M. (1996). Health and human rights. *BMJ: British Medical Journal*, 312(7036), 924.

- Mara, D. D. (2003). Water, sanitation and hygiene for the health of developing nations. *Public health, 117*(6), 452-456.
- Marmot, M., Friel, S., Bell, R., Houweling, T. A., Taylor, S., & Health, C. o. S. D. o. (2008). Closing the gap in a generation: health equity through action on the social determinants of health. *The Lancet, 372*(9650), 1661-1669.
- Marmot, M. (2007). Achieving health equity: from root causes to fair outcomes. *The Lancet, 370*(9593), 1153-1163.
- Marston, J. (2003). Doing a home visit. *Home-based HIV/Aids care, 115*-131.
- Marx, C., & Charlton, S. (2003). The case of Durban South Africa, Understanding slums: Case studies for the Global Report 2003. *Development Planning Unit, London*.
- Mills, A. (1983). Vertical vs horizontal health programmes in Africa: idealism, pragmatism, resources and efficiency. *Social Science & Medicine, 17*(24), 1971-1981.
- Misselhorn, M. (2010). A new response to informal settlements. *The Transformer, 15*, 16-20.
- Montgomery, M. A., & Elimelech, M. (2007). Water and sanitation in developing countries: including health in the equation. *Environmental Science & Technology, 41*(1), 17-24.
- Mouton, J., & Barbie, E. (2004). *The practice of social research*. Open University press.
- Mudey, A. B., Kesharwani, N., Mudey, G. A., & Goyal, R. C. (2010). A cross-sectional study on awareness regarding safe and hygienic practices amongst school going adolescent girls in rural area of wardha district, India. *Global Journal of Health Science, 2*(2), p225.
- Naidu, T., Slipe, Y., & Dageid, W. (2012). The social construction of identity in HIV/AIDS home-based care volunteers in rural KwaZulu-Natal, South Africa. *SAHARA-J: Journal of Social Aspects of HIV/AIDS, 9*(2), 113-126.
- Nanan, D., White, F., Azam, I., Afsar, H., & Hozhabri, S. (2003). Evaluation of a water, sanitation, and hygiene education intervention on diarrhoea in northern Pakistan. *Bulletin of the World Health organization, 81*(3), 160-165.
- Neuman, W. L. (2014). *Social research methods: qualitative and quantitative approaches*. Harlow: Pearson.

- Ngwenya, B. N., & Kgathi, D. L. (2006). HIV/AIDS and access to water: a case study of home-based care in Ngamiland, Botswana. *Physics and Chemistry of the Earth, Parts A/B/C*, 31(15), 669-680.
- Nnadozie, R. C. (2013). *Access to basic services in post-apartheid South Africa: What has changed? Measuring on a relative basis*: African Development Bank Group, Statistical Department.
- Okun, D. A. (1987). Value of water supply and sanitation in development: an assessment of health related interventions *WASH Technical Report* (Vol. 43): WASH Project.
- O'Rourke, E. (1992). The international drinking water supply and sanitation decade: dogmatic means to a debatable end. *Water Science & Technology*, 26(7), 1929-1939.
- Paquette, D., & Ryan, J. (2001). Bronfenbrenner's ecological systems theory. Retrieved on July, 30, 2008.
- Patton, M. (2002). *Qualitative research and evaluation* (3rd ed.). London: Sage.
- Potgieter, N., Koekemoer, R., & Jagals, P. (2007). A pilot assessment of water, sanitation, hygiene and home-based care services for people living with HIV/AIDS in rural and peri-urban communities in South Africa. *Water Science & Technology*, 56(5), 125-131.
- Potgieter, N., & du Preez, M. (2012). Health impact of water, sanitation and hygiene services in relation to home-based care for people living with HIV and AIDS in the Limpopo Province, South Africa. WRC Report.
- Potvin, L., & Jones, C. M. (2011). Twenty-five years after the Ottawa Charter: the critical role of health promotion for public health. *Canadian Journal of Public Health/Revue Canadienne de Sante'e Publique*, 244-248.
- Prüss, A., Kay, D., Fewtrell, L., & Bartram, J. (2002). Estimating the burden of disease from water, sanitation, and hygiene at a global level. *Environmental health perspectives*, 110(5), 537-542.
- Ritchie, J., & Lewis, J. (2003). *Qualitative research practice. A guide for social scientists*: London: Sage.

- Rödlach, A. (2009). Home-based care for people living with AIDS in Zimbabwe: voluntary caregivers' motivations and concerns. *African Journal of AIDS research*, 8(4), 423-431.
- Roma, E., Buckley, C., Jefferson, B., & Jeffrey, P. (2010). Assessing users' experience of shared sanitation facilities: A case study of community ablution blocks in Durban, South Africa. *Water SA*, 36(5).
- Rubin, H. J., & Rubin, I. S. (2011). *Qualitative interviewing: The art of hearing data*: Sage.
- Sahoo, K. C., Hulland, K. R., Caruso, B. A., Swain, R., Freeman, M. C., Panigrahi, P., & Dreibelbis, R. (2015). Sanitation-related psychosocial stress: A grounded theory study of women across the life-course in Odisha, India. *Social Science & Medicine*, 139, 80-89.
- Sanders, D. (2003). Twenty-five years of primary health care: lessons learnt and proposals for revitalisation. *Africanus*, 33(2), 45-60.
- Schaay, N., & Sanders, D. (2008). International perspective on Primary Health Care over the past 30 years: Primary Health Care: in context. *South African health review*, 3-16.
- Shaw, M. (2004). Housing and public health. *Annu. Rev. Public Health*, 25, 397-418.
- Shisana, O., Rehle, T., Simbayi, L., Zuma, K., Jooste, S., & Zungu, N. (2014). South African National HIV Prevalence, Incidence, and Behaviour Survey, 2012. Cape Town: Human Sciences Research Council; 2014.
- Snape, D., & Spencer, L. (2003). The foundations of qualitative research in J. Ritchie, & J. Lewis, (Eds), *Qualitative Research Practice: A guide for social science students and researchers* (pp.65-195). London: Sage.
- Somekh, B., & Lewin, C. (2005). *Research methods in the social sciences*: Sage.
- South African national sanitation policy. (1996). White paper. Retrieved from:
<https://www.dwa.gov.za/Documents/Policies/National%20Sanitation%20Policy.pdf>
- Spencer, L., Ritchie, J., & O'Connor, W. (2003). Analysis: Practices, Principles and Processes in J. Ritchie, & J. Lewis, (Eds), *Qualitative research practice: A guide for social science students and researchers* (199-250). London: Sage.

- Statistics South Africa (2007). Community survey: Basic Results Municipalities. Pretoria.
Retrieved from: <https://www.statssa.gov.za/publications/P03011/P030112007.pdf>
- Stewart, D. W., & Shamdasi, P. M. (1990). *Focus groups: theory and practice*. Newbury Park CA: Sage.
- Strunz, E. C., Addiss, D. G., Stocks, M. E., Ogden, S., Utzinger, J., & Freeman, M. C. (2014). Water, sanitation, hygiene, and soil-transmitted helminth infection: a systematic review and meta-analysis. *PLoS Med*, *11*(3), e1001620.
- Sultana, F., & Crow, B. (2000). *Water concerns in rural Bangladesh: a gendered perspective*. Paper presented at the WEDC conference.
- Swyngedouw, E. (2009). The Political Economy and Political Ecology of the Hydro-Social Cycle. *Journal of Contemporary Water Research & Education*, *142*(1), 56-60.
- Tarimo, E., & Webster, E. (1994). Primary health care concepts and challenges in a changing world: Alta-Ata revisited *Current Concerns. SHS Paper (WHO)*: World Health Organization.
- Terre Blanche, M. Durrheim. K. (1999). *Research in practice: applied methods for the social sciences*.
- Tibaijuka, A. K. (2004). Africa on the Move: an urban crisis in the making. *Report submitted to the UN-Habitat Commission for Africa*.
- Tsinda, A., Abbott, P., Pedley, S., Charles, K., Adogo, J., Okurut, K., & Chenoweth, J. (2013). Challenges to achieving sustainable sanitation in informal settlements of Kigali, Rwanda. *International journal of environmental research and public health*, *10*(12), 6939-6954.
- Ulin, P. R., Robinson, E. T., & Tolley, E. E. (2012). *Qualitative methods in public health: a field guide for applied research*: John Wiley & Sons.
- UN. (2005). The millennium development goals report. Retrieved from:
<http://unstats.un.org/unsd/mi/pdf/mdg%20book.pdf>
- UNAIDS. (2004). Global report on the AIDS epidemic. Retrieved from:

http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/documents/2004/GAR2004_en.pdf

United Nations Development Programme. (1980): Decade Dossier, International Drinking Water Supply and Sanitation Decade 1981 - 1990, New York.

UNESCO. (2006). Water: a shared responsibility. The united Nations World Water Development Report 2. Paris.

Unger, J.-P., & Killingsworth, J. R. (1986). Selective primary health care: A critical review of methods and results. *Social Science & Medicine*, 22(10), 1001-1013. doi: [http://dx.doi.org/10.1016/0277-9536\(86\)90200-5](http://dx.doi.org/10.1016/0277-9536(86)90200-5)

UN-HABITAT. (2003). The challenge of slums: global reports on human settlements. Retrieved from www.unhabitat.org/jo/pdf/GRHS.2003.pdf.

Walsh, J. A., & Warren, K. S. (1979). Selective primary health care: an interim strategy for disease control in developing countries. *New England journal of medicine*, 301(18), 967-974.

Walters, G. (1989). Decade Assessment Report. ESA Collaborative Council Meeting: Background Documents. WHO Publication.

Warner, D. (1990). Building the Collaborative Network: Co-ordination at the Global and Regional Levels. WHO Publication.

WaterAid Report. (2010). Access to water, sanitation and hygiene for people living with HIV and AIDS: A cross-sectional study in Nepal.

Watts, S. J. (1986). The comparative study of patterns of guinea worm prevalence as a guide to control strategies. *Social Science & Medicine*, 23(10), 975-982.

Watts, S. J. (1987). Population mobility and disease transmission: the example of guinea worm. *Social Science & Medicine*, 25(10), 1073-1081.

Wilder, A. R. (2009). *Ecological systems theory as applied to family care givers old aging adults in Arlington*. PhD thesis, University of Texas. Retrieved from http://www.who.int/water_sanitation_health/hygiene/iys/wwd_2008.pdf.

- Wisner, B., & Adams, J. (2002). *Environmental health in emergencies and disasters: a practical guide*. World health organization.
- World Health Organization. (1946). *Constitution of the World Health Organization*, as adopted by the International Health Conference, New York: signed 22 July 1946 by the representatives of sixty-one states (Official Records of the World Health Organization, no. 2, p. 100) and entered into force 7 April 1948. Retrieved from:
www.who.int/rarebooks/official_records/constitution.pdf.
- WHO & UNICEF. (1978). Declaration of Alma Ata: International Conference on Primary Health Care, Alma Ata, USSR. Retrieved from:
www.who.int/hpr/NPH/docs/declaration_almaata.pdf.
- WHO. (1981). Drinking - Water and Sanitation, 1981-1990. WHO Publication.
- WHO & UNICEF. (2006). Meeting the MDG drinking water and sanitation target, the urban and rural challenge of the decade. Retrieved from:
http://www.who.int/water_sanitation_health/monitoring/jmpfinal.pdf
- WHO (2008). Guidelines for drinking water quality. 3rd edition. Geneva:
http://www.who.int/water_sanitation_health/dwq/gdwq3rev/en/.
- WHO/UNICEF (2010). Joint Monitoring Programme for Water Supply and Sanitation. ISBN 978 92 4 156395 6 (NLM classification: WA 670)
- WHO (2011). Disaster Risk Management for Health WATER, SANITATION AND HYGIENE
- WHO & UNICEF. (2013). Progress on sanitation and drinking water update. Retrieved from:
http://apps.who.int/iris/bitstream/10665/81245/1/9789241505390_eng.pdf
- WHO & UNICEF. (2014). Progress on drinking water and sanitation update. Retrieved from:
http://www.wssinfo.org/fileadmin/user_upload/resources/JMP_report_2014_webEng.pdf
- WHO & UNICEF. (2015). Key Facts from JMP Report. Retrieved from:
http://www.who.int/water_sanitation_health/monitoring/jmp-2015-key-facts/en/

- WHO & UNICEF. (2015). Progress on Sanitation and drinking water-update and MDG assessment. Retrieved from:
http://www.unicef.org/publications/files/Progress_on_Sanitation_and_Drinking_Water_2015_Update_.pdf
- WorldWatch Institute (2007). State of the world 2007: Our urban future. Washington DC.
- Yacoob, M., Brieger, W., & WattS, S. (1989). Primary health care: why has water been neglected? *Health policy and planning*, 4(4), 328-333.
- Yallew, W. W., Terefe, M. W., Herchline, T. E., Sharma, H. R., Bitew, B. D., Kifle, M. W., Adane, M. M. (2012). Assessment of water, sanitation, and hygiene practice and associated factors among people living with HIV/AIDS home based care services in Gondar city. *BMC public health*, 12(1), 1057.

Appendix A: ETHICAL CLEARANCE LETTER



UNIVERSITY OF
KWAZULU-NATAL
INYUVESI
YAKWAZULU-NATALI

19 September 2014

Ms Chanelle Muloqi (209519502)
School of Applied Human Sciences – Psychology
Howard College Campus

Protocol reference number: HSS/0926/014M
Project title: Exploring water, sanitation, hygiene and wellbeing in home based care for people living with HIV/AIDS in Durban

Dear Ms Muloqi,

Full Approval – Expedited Application

In response to your application received on 04 August 2014, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted FULL APPROVAL.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I wish this opportunity of wishing you everything of the best with your study.

Yours faithfully

Dr. Sherryka Singh (Chair)

/ms

Co-Supervisor: Dr. Dlagolelo Adimola
Co-Academic Leader Research: Professor D. McCracken
Co-School Administrator: Ms Auzie Luthuli

Humanities & Social Sciences Research Ethics Committee

Dr. Sherryka Singh (Chair)

Westville Campus, Gwelo-Mbeki Building

Postal Address: Private Bag 354001, Durban 4001

Telephone: +27 (0)31 206 2000/206 2001/206 2002 Fax: +27 (0)31 206 4000 Email: ethics@uqn.ac.za / ethics@uqn.ac.za / ethics@uqn.ac.za

Website: www.uqn.ac.za

1918-2017
10 YEARS OF ACADEMIC EXCELLENCE

Faculty of Education | School of Applied Human Sciences | Howard College | Westville School | Faculty of Health Sciences | Westville

Appendix B: INFORMED CONSENT FORM

Dear Participant,

My name is Chanelle Mulopo. I am a Health Promotion Masters student studying at the University of KwaZulu-Natal, Howard College Campus. The title of my research is: *Water, sanitation and hygiene in community and home-based care for people living with HIV/AIDS/TB in Durban, South Africa*. The aim of the study is to explore the following, firstly; To explore water, sanitation and hygiene in community and home-based care for people living with HIV/AIDS/TB, secondly; To explore the challenges faced in home-based care by caregivers with regards to water, sanitation, hygiene and how they cope with these challenges and lastly; To explore how water sanitation and hygiene affects the general well-being of patients, family members of the patients and CHWs. I am interested in conducting focus group discussions with you so as to share your experiences on the subject matter.

Please note that:

- The information that you provide will be used for scholarly research only.
- Your participation is entirely voluntary. You have a choice to participate, not to participate or stop participating in the research. You will not be penalized for taking such an action. Participants have the right to withdrawal without any negative consequences.
- Your views in this interview will be presented anonymously. Neither your name nor identity will be disclosed in any form in the study.
- The focus group discussions will take about (40-45 minutes).
- All information recorded as well as other items associated with the research will be held in a password-protected file accessible only to myself and my supervisor. After a period of 5 years, in line with the rules of the university, shredding and burning will dispose it.
- If you agree to participate please sign the declaration attached to this statement (a separate sheet will be provided for signatures)
- The results to this research will be useful in generating knowledge on the status and challenges of water sanitation and hygiene in home-based care. The results will also

inform home-based care organizations of what could be done to improve the situation. The information generated from this study could also be used to inform policies on water, sanitation and hygiene with particular focus on HIV/AIDS patients in Home-based care.

I can be contacted at: School of Applied Human Sciences, University of KwaZulu-Natal, Howard College Campus, Durban. Email: cmulopo@gmail.com Cell: 073 5776016

My supervisor is Dr. Olagoke Akintola, who is located at the School of Applied Human Sciences, Howard College Campus Durban of the University of KwaZulu-Natal. Contact details: email akintolao@ukzn.ac.za Phone number: 031 260 7426

For information on your rights as a research participant contact Ms Phumelele Ximba, University of KwaZulu-Natal Research office: Tel: 031 260 3587.

Please complete the section below if you are willing to participate in the study.

Thank you for your contribution to this research.

Chanelle Mulopo

DECLARATION OF CONSENT TO PARTICIPATE IN THE STUDY

I _____ have read the information about this study and understand the explanations of it given to me verbally. I have had my questions concerning the study answered and understand what will be required of me if I take part in this study.

Signature _____ Date _____

Zulu Version

Incwadi Yemvume

Mina, _____ Sengfundile mayelana nokuqukethwe inhlolovo noma ngiyaqonda izincazelo zenhlolovo njengoba ngazisiwe futhi ngachazelwa ngazo ngomlomo. Isiphenduliwe imibuzo yami ngalenhlolovo, ngakho ngiyagonda ukuthi yini ebhekeke kimina uma ngiba yngxemye yalenhlolovu

Signature _____ Usuku: _____

Appendix C: INTERVIEW GUIDE FOR CHWs AND HBC MANAGERS/FOUNDERS

Main question	Follow up question	Probing question
1. What are your experiences with regards to water, sanitation and hygiene	<ul style="list-style-type: none"> (i) Micro-level: HIV/AIDS clients (ii) Meso-level: Family members of HIV/AIDS clients (iii) Exo-level: CHWs 	<ul style="list-style-type: none"> • Where do you get water? • How do you maintain sanitation and hygiene?
2. What are some of the challenges that you face with regards to water, sanitation and hygiene	<ul style="list-style-type: none"> (i) Micro-level: HIV/AIDS clients (ii) Meso-level: Family members of HIV/AIDS clients (iii) Exo-level: CHWs 	<ul style="list-style-type: none"> • What would you like to see be done about these challenges with regards to (WASH) • Who do you think is responsible in providing water, sanitation and hygiene in this community • How do you cope with these challenges
3. Has there been a situation when there is no water? If yes what do you do under such circumstances?		<ul style="list-style-type: none"> • How does limited access to water affect your work?
4. Can you please tell me about the conditions of homes and toilets in the households of PLWHA		<ul style="list-style-type: none"> • Who cleans the homes and toilets • Are the toilets accessible to the patients?
5. How is clinical waste from the patients disposed?	<ul style="list-style-type: none"> (i) Micro-level: HIV/AIDS client 	<ul style="list-style-type: none"> • Where is clinical waste disposed?

	(ii) Meso-level: Family members of HIV/AIDS clients	<ul style="list-style-type: none"> • How is clinical waste handled?
	(iii) Exo-level: CHWs	
6. Do you have all the necessary protective equipment needed to perform your duties such as gloves, masks and aprons etc.?		<ul style="list-style-type: none"> • Who provides protective equipment? • Have you been in a situation where you have lacked for instance gloves? What do you do in such a situation?

IsiZulu version

Main question	Follow up question	Probing question
1. Amazi, ukuthutwa kwendle, nenhlanzeko akuphate kanjani?	(i) Micro-level: Abantu abane HIV/AIDS (ii) Meso-level: Abantu emindeni abane HIV/AIDS (iii) Exo-level: CHWs	<ul style="list-style-type: none"> • Uwatholphi amazi? • Ukuthuka kwendle nenhlanzeko uyiqhubekisa kanjani?
2. Yiziphi izinkinga ohlangana nazo mayelana namanzi, ukuthutwa kwendle, nenhlanzeko?	(iv) Micro-level: Abantu abane HIV/AIDS (v) Meso-level: Abantu emindeni abane HIV/AIDS (vi) Exo-level: CHWs	<ul style="list-style-type: none"> • Ngabe yini izinto ongazi shintsha mayelana namazi, ukuthutwa kwendle nenhlanzeko? • Ngokucabanga kwakho, ubani umele anitholele amazini nokwenza indawo yomphakathi ihlanzeke? • Uzingoba kanjani izinkinga zamani,

		ukuthutwa kwendle nokuhluzeka?
3. Ike yabakhona isikhathi la mazi ayengekho khona? Uma uvuma, uwenzanjani kulesi simo?		<ul style="list-style-type: none"> • Ukungatholakali kwamazi ukwena usebenze kanjani?
4. Ngicela ungichazela ukuthi kuhlanzeke kangakanani endlini nasematoileti emakhaya ase PLWHA?		<ul style="list-style-type: none"> • Ubani uqoqayo endleni nasematoileti? • Iziguli ziyakwazi yini ukuwathola nokusebenzisa amatoileti?
5. Niwalahla kanjani izinto obuzi sebenzisa ngesikhathi ulapha umuntu?	<p>(i) Micro-level: Abantu abane HIV/AIDS</p> <p>(ii) Meso-level: Abantu emindeni abane HIV/AIDS</p> <p>(iii) Exo-level: CHWs</p>	<ul style="list-style-type: none"> • Uwalahlaphi izinto obuzi sebenzisa ngesikhathi ulapha umuntu? • Niwaphatha kanjani lezizinto zokulapha abantu?
6. Unazo zonke izinto ozidingayo uma udinga ukulapha umuntu njegama gloves, mask, apron, etc?		<ul style="list-style-type: none"> • Ubani unikayo izinto zokulapha umuntu? • Kube kwabakhona isikhathi la obengenzo izinto zokulapha abantu? Wenzanjani uma kunjalo?