

Work related conditions affecting  
community caregivers providing  
services to persons living with HIV and  
AIDS at *eMondlo* Township

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services to persons living with HIV and  
AIDS at *eMondlo* Township

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Department of Social Work

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## **DECLARATION**

I declare that this research is my own work, both in conception and execution and it has not been submitted anywhere for any degree or diploma. The information in this document is to the best of my knowledge true. Where other sources of information have been used, they have been appropriately acknowledged.

## **DEDICATION**

I dedicate this dissertation to my family. I wish to express a special gratitude to my loving parents Thomas and Goodness whose words of encouragement and push for tenacity ring in my ears, they have patiently supported me with the little they have throughout the process. I give special thanks to my family, they have been my best cheerleaders.

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## ABSTRACT

The study was about work related conditions affecting community caregivers on HIV/AIDS positive people at *eMondlo* Township, which is approximately 28 kilometres from Vryheid town in KwaZulu-Natal. Vryheid is located in the Northern part of KwaZulu-Natal province and forms part of the Zululand District Municipality. It has a population predominated of black people. Mondlo Township is the area that was established in 1963 as an exclusive African settlement through the process of forced removals according to the Apartheid Law of Group Areas Act of 1950. Many of whom individuals had freehold title to their land and residence were also removed from so-called “black spots” as well as farms surrounding Vryheid. The researcher’s intention was to establish how community caregivers are affected by their work, explore how community caregivers feel about their work related conditions and outline the consequences experienced by community caregivers. Community caregivers provide long term care to the community despite the challenges they encounter when executing their duties. The study was conducted at *eMondlo* Township using twenty four (24) participants from three different public health clinics. Eight (8) respondents were selected proportionally from these clinics. The researcher used qualitative research design. Content analysis was used to analyze data.

Findings of the study indicated that the community caregivers are affected by their work. Various challenges have been identified, namely, shortage of resources, lack of substantial food, poor service from clinics officials, travelling long distances on foot, lack of debriefing and less salary. These findings show that the community caregivers are depressed. They have accepted living with the burden of caregiving, whereas it is slowly damaging their self-esteem and affecting their lives. The study indicates that community caregivers are now doing their work simply because they are passionate and are attached to their patients. Even the little salary they earn is the only income they have to support their families which sometimes end up being used in performing their work.

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# CHAPTER ONE

## 1. ORIENTATION OF THE STUDY

### 1.1 Introduction

The researcher in this work conducted a study assessing work related conditions that affect community caregivers of HIV/AIDS positive people at *eMondlo* Township. The emphasis of this study was on establishment of work supporting systems necessary to improve work conditions of community caregivers. Today, *eMondlo* faces a serious backlog in infrastructure development. Even after almost twenty years of democracy and limited restitution through the finalization of land claims, the lack of opportunity and investment has led to high levels of crime and general poverty. The causes of all these problems can be directly traced to the destruction and forced removal of stable communities and the failures of apartheid social engineering. The effect of HIV/AIDS in South Africa especially in KwaZulu-Natal has contributed to a large number of people who are infected and affected by this pandemic. This has led to healthcare facilities getting overwhelmed by the large number of HIV/AIDS patients who require health services. Consequently, community caregivers' programme was introduced as an intervention at regional, national and international level in order to provide support for HIV/AIDS patients.

The national and regional goals within the caregiving programme were to strengthen and support the capacity of families to protect and care for orphans and other children made vulnerable by HIV and AIDS, to mobilize and strengthen community-based responses for the care, support and protection of orphans and other children made vulnerable by HIV and AIDS, ensure the legislation, policy, strategies, and programmes are in place to protect the most vulnerable. The other goal was to rise awareness and advocate for the creation of a supportive environment for orphans and other people made vulnerable by HIV and AIDS and strengthen mechanism to drive and support the implementation of the National Action Plan.

The community caregivers provide services that enable individuals of all ages to maintain their independence, dignity and quality of life within their homes and communities. Whenever possible, community caregivers offer non-medical assistance to local residents who are infected by HIV/AIDS so that they can avoid unnecessary hospitalization. The Integrated Social Services Framework (2011:1) indicated that the essential elements of community caregivers emanate from the National Community Health Work Policy Framework drafts of 2004. Furthermore, introducing community caregivers' programme was based on the findings by the Department of Health that most of the conditions affecting adults with HIV infection can be effectively managed at home, and that this can be most convenient and cost-effective for the individual and their family (Hunter, 2005:5). Based on personal observation, community caregivers at *eMondlo* Township are not entirely satisfied with their current working conditions.

## **1.2. Statement of the problem**

The community caregivers at *eMondlo* Township in the Northern part of Kwa-Zulu Natal province in south Africa are experiencing work related problems that cause them not to enjoy their community caregiving job and leads to stress and negative feelings about their daily job . Teasdale (2006:251) suggests that "every work involves some degree of pressure, but if it reaches excessive levels it can contribute to severe consequences including mental and physical illness." If the work related problems affecting community caregivers at *eMondlo* Township persist, it would be detrimental to the home based care programme and even more for HIV/AIDS patients themselves. These caregivers have to cope with the emotional and physical demands of stressful jobs, their family circumstances, low salaries and increasing economic pressure. Seeing that most of the caregivers are women, they specifically have to cope with feelings of frustration, anxiety, exhaustion, anger, depression, increased use of alcohol and other substances, a reduced immune response, poor physical health and more chronic conditions and neglecting their self-care.

Caring for someone whose mobility and bodily functions have deteriorated can place great demands on the overall bio-psycho-social functioning of caregivers (Barker, 2014: 41). Carers may risk their physical health when assisting someone, perhaps heavier than themselves, with tasks such as getting out of bed or moving around the

home (WHO, 2012). In addition, most caregivers are ill-prepared for their role and have to provide care with little or no support, yet more than one-third of caregivers continue to provide intense care to others while suffering from poor health themselves (Buhr et al., 2006:46-61). The provision of home based care services, which deal with vulnerable persons, should not place an additional burden on community caregivers. Undertaking this study helped the researcher to assess the working conditions of community caregivers in order to create a platform of advocacy to suggest positive changes to the circumstances of caregivers.

HIV and AIDS in South Africa is a prominent health concern. South Africa is believed to have more people with HIV and AIDS than any other country in the world. It is revealed that worldwide statistics for people living with HIV and AIDS is 36,7 million and they are all accessing treatment globally, nationally is 07 million people living with HIV and AIDS and within the district is 35% people who are living with HIV and AIDS.

South Africa national has the biggest and most high profile HIV epidemic in the world, with an estimated 7 million people living with HIV and in Kwa-Zulu Natal the HIV prevalence is almost 40%.

The duties of the community caregivers would not be discharged fully given the unfavorable working conditions. Ultimately, community caregivers at *eMondlo* Township would dislike their job. The provision of home based care services should not place a burden on community caregivers, especially as they are dealing with vulnerable patients. Undertaking this study helped the researcher to assess the working conditions of the community caregivers at *eMondlo* Township.

### **1.3. Motivation of the study**

As a social worker working closely with community caregivers, it has been challenging given their working conditions while caring for the HIV/AIDS patients. The researcher observed that community caregivers often complain about their conditions of services as community caregivers. During the informal conversations the researcher had with few community caregivers, it emerged that there were numerous work related conditions that prevented them from performing their duties. Emphasis was on the shortage of resources that did not enable them to do their work adequately.



Consequently, HIV/AIDS patients do not receive proper health care services from community caregivers. That is contrary to one of the *Batho Pele* Principles, namely “Courtesy”, wherein it is emphasized that people must be treated with courtesy and consideration. This drove the researcher to conduct a study to establish the work conditions of community caregivers with an aim of addressing their concerns.

## **1.4 Aim of the study**

The study aims to assess work related conditions affecting community caregivers providing services for persons with HIV/AIDS at *eMondlo* Community.

## **1.5 Objectives of the study**

The objectives of the study were:

1. To establish how community caregivers are affected by their work related conditions.
2. To explore how community caregivers feel about their work related conditions.
3. To assess the work related condition that affect community caregivers at *eMondlo* Township.
4. To outline work related consequences experienced by community caregivers.

## **1.6. Research questions**

In order to achieve the objectives of the study, the study would answer the following questions:

1. How work related conditions affect community caregivers?
2. What are the impacts of home based care programme on caregivers?
3. What would caregivers contribute towards improving community caregiving work?
4. What are the experiences of community caregivers?

## **1.7. Definition of terms**

The following terms are defined in order to eliminate misunderstanding about the conceptualization of terms.

### **1.7.1 Community caregiver**

Community caregiver is a person who gives direct care to people who cannot do things on their own (Britain et al 2007:65).

### **1.7.2 Human immunodeficiency virus**

Human immunodeficiency virus (HIV) is the virus that causes Acquired Immune Deficiency Syndrome (AIDS) and damages cells of the body immune system particularly cells called CD4 count (Eeste & Cihlar 2010).

### **1.7.3 Acquired immune deficiency syndrome (AIDS)**

Acquired immune deficiency syndrome is a chronic, potentially life-threatening condition caused by the human immunodeficiency virus. AIDS is currently defined as an illness characterized by the development of one or more AIDS indicating conditions. It is diagnosed in people infected with human immune deficiency virus (HIV) when they develop certain opportunistic infections for the first time (Thompson et al 2012).

## **1.8 Significant of the study**

1.8.1 The findings of the study would be used to policy makers in the Department of Health as it highlights the importance of community caregivers towards HIV/AIDS positive people at *eMondlo* Township.

1.8.2 The study provides detailed and comprehensive understanding on the work related conditions affecting community caregivers and the significance of community caregivers towards HIV/AIDS positive people.

1.8.3 The study will assist future researchers to verify whether the recommendations of this study were implemented because the findings will be taken as a reliable source of empirical or observed data.

## **1.9. Limitations of the study**

The issue of HIV and Aids is still very sensitive to community caregivers as they do not have sufficient information and when the researcher visited them, they were very reluctant to participate. Community caregivers felt uncomfortable and were afraid

that the researcher was invading their patients privacy. It is also important to note that the result of this study cannot be generalized to the whole population. Although the above restrictions that the researcher met, the limitation were overcome by ensuring the respondents confidentiality and anonymity of the information gathered. The information gathered in this study is limited to *eMondlo* Township and Vryheid Hospital.

### **1.10 Research Location**

The research would be conducted at *eMondlo* Community. The nearest town is Vryheid. *EMondlo* Township is in Zululand District under Abaqulusi Municipality. Abaqulusi Local Municipality is located in the Northern part of KwaZulu-Natal province and forms part of the Zululand District Municipality (Abaqulusi Local Municipality IDP, 2015/2016). *EMondlo* area is in the Northern part of the province of KwaZulu-Natal in South Africa

### **1.11 Preliminary Literature review**

This study reviewed relevant books and accredited journal articles relating to community caregiver and conditions that affect employees' performance. Government legislation and other publications that relate to community caregiving were also part of the literature review. The purpose of reviewing the highlighted documents was to see in detail different perspectives of community caregivers and their experiences at work. The main focus in this study was on the work related conditions of community caregivers on HIV/AIDS positive people at *eMondlo* area.

#### **1.11.1. Challenges faced by community caregivers (CCGs) at work**

"HIV has placed a heavy burden on caregivers especially in South Africa where an estimated 5.5 million people were living with HIV in 2006, and where an estimated one in every three to four patients admitted to some public hospitals is HIV-positive. Occupational stress and burnout merit concern in South Africa as the severity and intensity of HIV epidemic is often perceived as overwhelming, leaving many caregivers with intense feelings of hopelessness and despair" (van Dyk, 2007). They usually battle with bereavement overload, over-identify with their patients, fear of occupational exposure to HIV, and find it difficult to cope with their own and patients stigmatisation and confidentiality issues (ibid).

In the view of Baum and Posluszny (2008:137-163), caregivers were generally not trained adequately to offer HIV-related counselling and other health services. Caregivers largely felt unsupported by their employers, family and friends (van Dyk, 2007). Consequently, caregivers developed the feeling of discontent with governmental processes including the misleading health messages about their roles as community caregivers. Caregivers who worked in different capacities found HIV-care-related factors equally stressful (van Dyk, 2007). The results clearly indicate that “caregivers sometimes worked in extremely difficult circumstances and require support from their employers to prevent burnout” (Beardslee, Gladstone, Wright and Cooper, 2003:112). Evidence now abounds on the unequal AIDS related care work responsibilities which were assumed disproportionately by girls and women as compared to boys and men (UNAIDS, 2008).

Although the caregiving impact on women is most visible in Africa, the trend is growing across the developing world (UNAIDS, 2008). Two thirds of people living with HIV and AIDS are nursed at home by their parents, usually their mothers. Older women and married women are significantly affected (ibid). “Care responsibilities fall to older women because a substantial proportion of people living with HIV and AIDS move back to their communities of origin at some stage of the illness to be cared for by their parents, and women take responsibility for their grandchildren where necessary” (UNAIDS, 2008).

### **1.11.2. Common psycho-social problems in caregiving**

According to Sherman (2000:151), “the emotional stress on caregivers of all ages can be significant. Children without adult supervision, having experienced the grief of losing their parents, face the responsibility of feeding and clothing their siblings which puts them at risk of exploitation and harm”. Parents caring for numerous children of their extended families and neighbours increase their worry and anxiety (UNAIDS, 2008). “Some adults care for their partners and loved ones, and for those that do not return to health, experience the pain of watching them die. Many of those in caregiving roles are also themselves living with HIV. This can cause additional psycho-social trauma for the caregiver. Many grandparents, parents and other carers often find that they have little time to grieve as they have to be emotionally and

physically strong to support and look after the dependent children left behind. The demanding nature of caring for both sick adults and children means carers can face social isolation” (ibid). Older women who look after grandchildren that have lost their parents to HIV/AIDS does not mean their parenting role would come easy simply because they have been parents in the past (Castro & Farmer, 2005:53).

## **1.12 Research Methodology**

The research methodology provides the framework on which the research would be built. Furthermore, it describes the methodological processes and procedures that a researcher applies in the course of the study.

Research methodology considers and explains the logic behind research methods and techniques (Welman, et al 2005:01). It is the strategy of enquiry, which moves from the underlying assumptions to research design and data collection (Thomas, 2010). Although there are other distinctions in the research mode, the most common classification of research methods is into qualitative and quantitative (ibid). At one level, qualitative and quantitative refer to distinctions about the nature of knowledge on how one understands the world and the ultimate purpose of the research (ibid).

### **1.12.1 Research design**

Research design is a detailed outline of how an investigation will take place. A research design will typically include how data is to be collected, what instruments will be employed, how the instruments will be used and the intended means for analyzing data collected. It focuses on the end-product of the study that is being planned and what kind of result are aimed at. It looked on the logic of research (Roller 2009:45). The research study adopted qualitative research methods, but have also integrated elements of a quantitative approach. Qualitative research methods are to establish the socially constructed nature of reality, to stress the relationship between the researcher and the object of the study as well as to emphasize the value-laden nature of the inquiry (Welman, et al 2005:09). This was done particularly to get holistic views on the experiences of the community caregivers. Qualitative research methods are used to gain insight into people’s attitudes, behaviour, values systems, concerns and motivations. The design enables the researcher to collect the data in the field at the site where participants experience the issue or problem under investigation (Creswell, 2009:181).

The study would qualitative research design. In qualitative research methods, a researcher collects data in the field or at the site where participants experience the issue or problem under investigation. In this study the researcher collected data in the field where respondents are required to provide information about their experiences as community caregivers. In qualitative research the information is gathered by talking to people and observing their behaviour (Creswell, 2009:181). That is possible in cases where the researcher goes to the place where respondents are.

### **1.12.2 Population**

Neuman (2006:224) defines population as a large pool of cases or elements, such as persons, groups of people, organisations, written documents, symbolic messages and even social actions under investigation. In a large group a researcher draws a sample from which results can be generalized. Population is any group that is the subject of research interest (Naude, 2002:46). The population for this study consists of community caregivers working at *eMondlo*. This population was targeted to provide the study with relevant responses regarding the normal experience in the work of being a community caregiver for HIV/AIDS patients. These caregivers were employed by the Department of Health, and the researcher consulted with the Department of Health to gain access to them. The size of the population was sixty five community caregivers working under the Department of Health.

### **1.12.3 Data collection procedures**

Data collection is the process of gathering and measuring information on variables of interest, in an established systematic fashion that enables one to answer stated research questions, test hypothesis, and evaluate outcomes (Mouton, 2001). The data collection component of research is common to all fields of study including physical and social science, humanities and business (Stellenbosch University library, 2016). While methods vary by discipline, the emphasis on ensuring accurate and honest collection remains the same (Ibid).

#### **1.12.4 The importance of ensuring accurate and appropriate data collection.**

Regardless of the field of study or preference for defining data (quantitative, qualitative), accurate data collection is essential to maintaining the integrity of research. Both the selection of appropriate data collection instruments (existing, modified, or newly developed) and clearly delineated instructions for their correct use reduce the likelihood of errors occurring (Most et al 2003:103).

#### **1.12.5 Sampling**

Sampling is the act, process, or technique of selecting suitable respondents, or a representative part of a population for the purpose of determining parameters or characteristics of the whole population. This study used random sampling technique to select participants. Punch (2005:102) suggests that in random sampling each element in the population has an equal chance to be chosen.

The township of *eMondlo* had three public health clinics, namely *Thembumusa*, *Bhekumthetho* and *Mondlo 2*. *Thembumusa* had twenty four (24) community caregivers, *Bhekumthetho* had sixteen (16) community caregivers and *eMondlo 2* had twenty five (25). Out of the total of 65 community caregivers 24 were purposively selected in order to represent all three sites (Grinell &Unrau, 2014:309). The researcher experienced that twenty four (24) would be representative of the whole population of community caregivers working in *eMondlo* Township. Eight (8) respondents would be selected proportionally from the three public health clinics at *eMondlo* Township.

#### **1.12.6 Data collection**

The study would use face-to-face interview to collect data. Punch (2005:172) asserts that this type of interview is a non-standardised, open-ended, in-depth, and is used as a way of understanding the complex behaviour of people. This approach is useful when the study is interested in discovering the respondents' personal experiences about a particular phenomenon.

Face to face interview it is also a data collection method when the interviewer directly communicates with the respondents in accordance with the prepared questionnaire. This method enables to acquire factual information, participants evaluations, attitudes, preferences and other information coming out during the conversation with the respondent. Thus face to face interview method ensures the quality of the obtained data and increase the response rate. In this study respondents provided the researcher with their own insight on the community caregivers' working conditions at *eMondlo* Township. The researcher prepared a set of questions that were asked to each respondent.

In this study respondents were providing the researcher with their insight on the community caregivers' working conditions at *eMondlo* Township. The researcher prepared the sets of questions that were administered to each respondent in a standardised manner. During unstructured interviews, the researcher proposed to use a tape recorder to get accurate data. The researcher then requested permission from respondents to record the interview process and the permission was obtained from the Department of Health.

### **1.12.7 Data analysis and interpretation**

Struwig and Stead (2007:169) assert that "data analysis methods enable the researcher to organise and bring meaning to the large amount of data". Content analysis was used in this study. In content analysis themes were extracted from the responses of the respondents. In doing data analysis using content analysis approach, themes and sub-themes were extracted through coding, elaborating, interpreting and then checking the data (Terre Blanche, Durrheim, & Painter, 2006:322). Qualitative data may take the form of interview transcripts collected from research participants or other identified texts that reflect experientially the topic of the study. Qualitative data is a systematic approach used to describe life experience and give them meaning. The goal of qualitative data is to gain insight, explore the depth and complexity inherent in the phenomenon. It examines the uniqueness of individuals lived situation and each person has their own reality. Data interpretation follows by qualitative data through themes and sub-themes means of synthesizing responses provided by the respondents, thus the researcher is able to attach meaning to the findings.



### **1.13. Ethical considerations**

Ethical consideration is an accumulative of values principles that address questions of what is good or bad in humans affairs (McDonald, M. (2003). Ethical aspects of the study have been effectively addressed as proposed by McDonald (2003) in the following manner:

The researcher also sent a letter requesting the Department of Health to conduct the study. The identity of individuals from whom information was obtained was kept strictly confidential. No information revealing the identity of any individual was included in the final report or in any other communication prepared in the course of the study.

Participants were informed that the data collected from them would be treated with the highest level of confidentiality; they were also informed about their right to withdraw participation in the study, should they feel uncomfortable at any time. Permission to record interviews was also requested and obtained from respondents. The participants signed a consent form before participating in the study.

The researcher ensured that confidentiality and anonymity was maintained throughout. Respondents have participated in the study voluntarily and have been fully informed about the aims and objectives of the study, the questionnaires did not contain any degrading, discriminating or any other unacceptable language that could be offensive to any members of the sample group, the questionnaire has been designed to collect information directly related to the research questions, and no private or personal questions were asked from respondents (adapted from Yilma, 2013). Permission to conduct the research study was obtained from the University of Zululand's Ethical Committee and from the Department of Social Work as well as Department of Health under Zululand District.

### **1.15 Summary**

Challenges experienced by community caregivers ruin their temper in performing as expected. The service providers are not flexible enough to meet community

caregivers' needs. This has resulted to the huge number of caregivers who are dropping out. The community caregivers encountered several challenges but they suggested possible solutions. The caregivers are not motivated and are poorly equipped in terms of skills, both emotionally and psychologically, and all these factors interplay to have a negative influence on the quality of care .The programme calls for government intervention and for other organisations involved in care delivery to increase their assistance, monitoring and surveillance of service delivery in order to improve the programme's of service delivery.

## **CHAPTER TWO**

### **2. Literature Review**

#### **2.1. Introduction**

This chapter presents literature review which focuses on the central concepts relating to the process of caregiving. In Hart's (2007) view, literature review can be viewed as the selection of available documents (both published and unpublished) on the topic, which contains information, ideas, data and evidence written from a particular standpoint to fulfill certain aims. This chapter provides insight into caregiving, community caregivers in caring for the HIV/AIDS positive people, home based and community based care and conditions faced by community caregivers at work in the caring of HIV/Aids positive people. The study also touches on psychosocial theory, exchange theory and modernization theory which serves as underpinning of theoretical framework. Strategies for effective caregiving will be discussed looking at the interventions done towards HIV/AIDS positive people.

According to the Caregivers Action Network (CAN) (2013), South Africa has a long history of community participation and mobilisation organised through civil society structures as well as community care provision to vulnerable communities through community home based care (CHBC) programmes. Community caregiver programmes played an important role in supplementing and redressing the effects of apartheid and in supporting the process of reforming the health system in the period before the democratic election in 1994 (ibid). While the new democratic government did not implement a national community caregiver programme post 1994, there was a large increase in community caregiver activity in response to the HIV epidemic and the overburdened public health system in the late 1990s and early 2000s (ibid).

CAN (2013) maintains that, it is until recently that the South African national government has relied mainly on partnerships with a wide array of NPOs to deploy community caregivers in impoverished communities. Thus, while the government has striven to provide enabling environments and funding, many NPOs operating at community level still take on basic care delivery, as well as the tasks of enrolling, training and managing community caregivers; paying their stipends or salaries; and

integrating their services within existing health and other social structures (ibid). CAN (2013) states that these NPOs range from small community-based organisations (CBOs) performing basic care and support services within the home environment in resource-constrained communities to well-resourced national and international NPOs offering care and support or fulfilling training and managerial roles. Across the nine provinces there has been considerable variation in the conditions of service of community caregivers, the extent of formalisation of their employment, the location of their work within or outside health facilities and in their remuneration (ibid). They provide a broad spectrum of health-related as well as social services, including more targeted specialised care (Friedman. (2005:65).

## **2. 2. Background of caregiving**

Community caregivers were chosen because of good history and standing. They were formed in 1990 and came into operation in 1993. Caregiving was promoted by the conservative government as a revolution in social care. Caregivers provide non-medical services to clients by helping them maintain independence. Families leaving with people who are affected by HIV/AIDS were assisted by community caregivers who provided long-term caregiving and counselling to the family members. Community caregivers were expected to help priority groups such as dependent elderly, people with long term mental health problems in their own homes. The principle of community care has been accepted by the government.

The history of community care policy could be described as patchwork of broken promises and moral posturing. Caregiving process helps out in providing care and assistance to another individual when that person cannot self-assist. Caregiving was publicized as a hard job, because it needed caregivers to be emotionally, physically and mentally powerful; that is why they are keen to attend workshops where they are able to discuss and share challenges they come across when doing their work. Being a caregiver for a person living with HIV/AIDS requires one to reorganise priorities, lifestyle and time. They do that because the task of caring for a person living with HIV/AIDS makes their lives more sensitive and lowers their self-esteem.

The demands inherent in the caregiving work results in many caregivers

experiencing tension, which leads to burnout, misery and other psychological problems (Anderson, 2010). Formal and informal caregivers often experience tension because the nature of their work is common in many respects. Community caregivers are at risk of being depressed, of having elevated levels of hostility and anxiety as well as concerns over insufficient time, loss of self-esteem and missed social opportunities (Koerner, 2009).

Literature reveals that community caregivers' physical life can be compromised (Chenier, 2002) but negative outcomes remain an important focus of caregiving. Caregiving benefits, in Baronet's view (2003), include feeling more useful, feeling needed, learning modern skills and adding meaning to one's sense of self. It also consists of gaining a sense of fulfillment for meeting a duty and enjoyment derived from caregiving itself (Koerner, 2009). It is realised that becoming a caregiver is a time of transition that requires a restructuring of patients' goals. No matter how difficult the role, becoming a community caregiver can give birth to new skills and new strengths. Living and being able to cope with the stress of caregiving is part of the art of caregiving.

### **2.3 Community caregivers in caring for the HIV and AIDS positive people**

Community caregivers help people within their residence. The services that they deliver include physical, psychosocial, sedative and spiritual intervention. Aids related care is part of the wider and large invisible care economy (UNAIDS, 2008). It includes child and elderly care which takes place largely at homes. It extends to the provision of food, daily care and transport for hospital visits is often required. It is well recognised that the majority of care work has increased due to illnesses that occur within the household. As a social worker, the researcher noted that the community caregivers find it difficult to perform their duties as expected due to the shortage of resources.

The costs of care are largely hidden and are generally not accounted in national statistics (UNAIDS, 2008). The community caregivers have been considered in the context of public health and macroeconomic policies addressing the broader care

economy (ibid). The promotion of providing care in the home may be a cost-effective strategy for government and private sector. There is little consideration for the physical, emotional and economic cost to households and to community caregivers themselves. The Department of Health has the responsibility of co-ordinating the development and promotion of youth development initiatives, establishment of youth desk and youth structures and implementation of procedures, reporting and upliftment of youth programme.

They take additional burdens, many of whom are often poor and themselves living with HIV/AIDS. “The impact of the burden of care is greater in resource-poor settings, particularly for rural and grassroots caregivers and for those that coordinate home based care programmes” (Lopez, Mathers, Ezzati, Jamison & Murray, 2006:149).

## **2.4 Community caregivers role**

According to CAN (2013), “Caregivers’ roles have tended to shift from generalist to specialist, and back to generalist, in response to the contours of the HIV epidemic, as well as to the ways in which funding has prioritised the pandemic over other illnesses. Before the advent of HIV, caregivers’ roles in South Africa tended broadly to target health conditions related to poverty, social inequality and migrant lifestyles, but these roles shifted to focus on basic physical care and other support required by clients and their families within the home environment as the HIV epidemic worsened during the 1990s”. Once ART became more available from around 2004, a diversification and specialisation of roles occurred in the areas of testing, counselling and monitoring adherence to medication, in addition to services already provided such as psychosocial support, care for orphans and vulnerable children (OVC) and socioeconomic support for those infected with and affected by HIV (UNAIDS, 2013). More recent policy moves by the National Department of Health have again been towards a more generalist ‘community health worker’ who will primarily play a surveillance and health promotion role in communities, map health conditions at a population level and advise and refer at-risk individuals and households to appropriate care, support and treatment (WHO, 2008). On the whole there is a trend towards integration of specialist roles and incorporation of conditions other than HIV/AIDS, most notably the integration of HIV and TB services (ibid).

In a study conducted by CAN (2013), research respondents raised concerns about the focus on state-employed 'community health workers' under new government policy, in light of the broad range of care and support roles that are currently being offered by community caregivers based in NPOs (largely funded by the Department of Health). A concern was that some elements of the spectrum of care and support, most notably home-based care, may no longer be provided if 'community health workers' became the only cadre of workers funded by the Department of Health (ibid). These roles include day-to-day basic physical care and support of long-term bedridden and terminally ill clients within their home environment, long-term psychosocial support, assistance with securing livelihoods through accessing social grants or generating income, counselling and regular drug adherence support in cases where it is necessary (ibid).

## **2.5 Caregivers' potential**

Similar to the study conducted by CAN (2013), this section covers the important roles played by caregivers in health promotion programmes, counselling and testing, client advocacy, stigma mitigation and community mobilisation all of which contribute to prevention of HIV or increased uptake of treatment. The role that is played by caregivers cannot be understated. They are involvement start from prevention, conducting awareness campaigns, connecting clients to treatment sites and monitoring adherence to ART. Likewise, they are becoming increasingly involved in surveillance for TB and other opportunistic infections, as well as monitoring side effects of ART (CAN, 2013). Caregivers clearly have the potential to effectively contribute to an expansion of HIV prevention, treatment and primary care programmes, provided they receive adequate support, including supervision and training (WHO, 2013).

CAN (2013) has reported on how organisations which focus on care and support offer promising potential models for delivering a broad range of services at local level while working closely with the formal health system. They can, for example, offer services covering a wider range of infectious diseases, maternal and child health, and non-communicable diseases (ibid). Additionally, they can offer services that

could be utilised for the implementation of the 'Treatment 2.0' framework, one objective of which is to increase the use of HIV prevention and treatment services through community-based approaches, provided that caregivers receive the required support and training. Several care organisations expressed an interest in expanding services, including direct ART provision (ibid).

## **2.6 Challenges faced by community caregivers at work**

According to Van Dyk (2007), HIV has placed a heavy burden on caregivers especially in South Africa where an estimated 5.5 million people were living with HIV in 2006, and where an estimated one in every three to four patients admitted to some public hospitals is HIV-positive. Occupational stress and burnout merit concern in South Africa as the severity and intensity of the HIV epidemic is often perceived as overwhelming, leaving many caregivers with intense feelings of hopelessness and despair (ibid). They usually battle with bereavement overload, over-identify with their patients, fear of occupational exposure to HIV, and find it difficult to cope with their own and patients' stigmatisation and confidentiality issues.

Baum and Posluszny (2008:137-163) believe that caregivers are generally not trained adequately to offer HIV-related counselling and other health services. Caregivers largely feel unsupported by their employers, family and friends. Consequently, they develop feelings of discontent with governmental processes including the misleading health messages about their roles as community caregivers. Caregivers working in different capacities found HIV-care-related factors stressful. The results clearly indicate that caregivers sometimes work in extremely difficult circumstances and require support from their employers to prevent burnout. Evidence now abounds on the unequal AIDS related care work responsibilities which are assumed disproportionately by girls and women as compared to boys and men (UNAIDS, 2008).

Community caregiver is the first line of support between the community and various health and social development services. It plays a vital role in supporting and empowering the community members to make informed choices about their health and psychosocial well-being and provides ongoing care and support to individuals and families who are vulnerable due to chronic illness and living circumstances. The



community caregivers believe in creating a better life for all individuals within the communities. Community caregiver is an individual who voluntarily provides ongoing care and support to individuals and families who are vulnerable due to illness and living circumstances.

Caring for individuals, families or anyone with a serious chronic illness is a physical and emotional challenge for even the most dedicated caregivers. This is particularly true for nurses, counsellors, volunteers and community caregivers in the home who provide most of the care for people living with HIV (PLHIV) and other chronic conditions.

Community caregivers work under stressful conditions which may lead to disillusionment and burnout. They need support to do their jobs well, remain infection-free and avoid burnout to ensure that the sustainability and quality of their services are not compromised.

The home and community based care (HCBC) policy framework is based on a holistic care and support model that also addresses the diverse needs of community caregivers to promote their overall wellbeing. The framework identifies the following five independent but inter-related components: Social support, which includes peer support, emotional and psychological support, which includes general counselling, Bereavement counselling, as well as related debriefing, supervision and mentorship and debriefing sessions to relieve stressful situations.

Although the caregiving impact on women is most visible in Africa, the trend is growing across the developing world in which two thirds of people living with HIV and AIDS are nursed at home by their parents, usually by their mothers. Older women and married women are significantly affected. Care responsibilities fall to older women because a substantial proportion of people living with HIV and AIDS move back to their communities of origin at some stage of the illness to be cared for by their parents, and women take responsibility for their grandchildren where necessary (Beardslee *et al.*, 2003:112).

## **2.7 Psycho-social problem in caregiving**

According to Sherman (2000:151), “the emotional stress on caregivers in all ages

can be significant. Children without adult supervision, having experienced the grief of losing their parents, face the responsibility of feeding and clothing their siblings which puts them at risk of exploitation and harm". Parents caring for numerous children of their extended families and neighbours increase their worry and anxiety (ibid). Some adults care for their partners and loved ones and, for those that don't return to health, experience the pain of watching them die. Many of those in caregiving roles are also themselves living with HIV, this can cause additional psycho-social trauma for the caregiver (UNAIDS, 2008). Many grandparents, parents and other carers often find they have little time to grieve as they have to be emotionally and physically strong to support and look after the dependent children left behind (ibid). The demanding nature of caring for both sick adults and for children means those carers can face social isolation. "Older women who looks after grandchildren who have lost their parents to HIV/AIDS, their parenting role does not necessarily come easy to them simply because they have been parents in the past" (Castro & Farmer, 2005:53).

## **2.8 The family context of caregiving**

The increasing number of fragile elderly encompasses a fast rising number of patients who are chronically ill. In response to this need, family members have assumed many tasks of giving care in the home (Davidhizar, 2009). Most home health services for older people with functional and health care needs are provided by the informal health care system, particularly family members. Most of the dependent elderly populations dwell at their own or at a family home. The relatives, known as informal caregivers, provide most of the assistance for the necessary activities of daily living, such as: feeding, bathing, dressing, toileting, among other things (Lopez et al., 2005). Results from the study conducted by Mohide (2002) indicate that a large proportion of these caregivers experience physical, emotional and social burden as a result of carrying this responsibility. According to Lopez et al (2005), only a small proportion of the dependent elderly is in nursing homes or is attended by professional formal caregivers.

Most caregiving is performed by the women in the families and mostly by daughters. Karner (1998) notes that general caregiving tasks are seen as compatible with the

traditional female role. It is estimated that more than 10 million people are involved in parent care, approximately half of whom provide care on a regular basis. Baldwin (2008) asserts that more than half of the elderly caregivers are wives; the next largest group of caregivers is daughters and daughters-in-law. Indeed, today the average woman will spend more time providing care for her parents than for her children. Eliopoulos (2005) makes reference that one in sixty full-time workers is a caregiver, and one in twelve is a potential caregiver. Families provide many types of assistance for their older members. The provision of assistance is often a subtle, gradual process. For example, a daughter may begin by telephoning her mother after the mother has returned from a physician's visit and inquiring about medication changes. As time progresses, the daughter may accompany her mother to the physician's office, discuss the medication directly with the physician, and telephone her mother to monitor the response to the drug. Eventually, the daughter may need to lift her mother in and out of the car, push her into the physician's office in a wheelchair, undress her for the examination, and administer the medications to her on a regular basis (Eliopoulos, 2005).

Baldwin (2008) estimates that about 5 million of all elderly live with an adult child. Family caregiving can carry numerous stresses, accumulated strain, and for some, a sense of burden. As the dependency (both physical and psychological) of an aging adult increases, conflicts may arise, placing stress on various individuals and the family system as a whole (Eliopoulos, 2005). According to Eliopoulos (2005), unresolved family issues or conflicts may be heightened by the physical, emotional, and often financial strain of caregiving. With the increasing number of women in the work force today, the added responsibility of giving care to a parent can create tremendous pressures for the adult daughter and her spouse and children. Adult children often report feeling reluctant and resentful in assuming a parenting role in the care of their own parent. The increasing dependency of the frail elderly raises many concerns related to the role reversal between parents and adult children. This role reversal situation may become especially difficult for middle-aged women who care for an adult parent in addition to their own spouse, children, and sometimes grandchildren (Eliopoulos, 2005).

Grunfeld et al, (2006) adds that, “family caregivers of terminally ill elders experience significant psychosocial, physical and economic burden, which negatively affects their quality of life”. Family caregivers report substantial financial losses associated with the role of caregiving. These include direct out-of-pocket expenses and lost wages because of time taken off work (Wagner and Lacey, 2004). The widely held view that home-based care is more cost-effective than institutional care does not take into account the indirect costs (opportunity costs, lost wages and family labour costs) borne by elders and their families. In fact, when family costs are included in the analysis, caring for an elderly with a terminal illness at home is no less expensive than caring for the same in an old age home (Grunfeld et al,2006).

Caring for a frail parent is not easy. Besides the obvious monetary expense, caring for a parent exacts a high psychological cost. Even the most devoted child has feelings of depression, resentment, anger and guilt at times. Many middle-aged adults have just come through the financial expenses associated with child rearing and may need to plan for their own retirement. The additional burden of a frail parent puts considerable pressure on resources that were earmarked for other uses. These difficulties are especially acute for the children of victims of chronic conditions (Cavanaugh, 2006). Research overwhelmingly shows how caregiving for dependent elderly subjects generates emotional and physical distress on relatives (Durant & Christian, 2006; Rabin, Bressler & Prager, 2004). Thus, as noted by Lopez (2005), caregivers get ill more often than those who are not caregivers; their immune response is reduced and they feel, on many occasions, overwhelmed by the burden of the care, as well as by anxiety, anger and depression. In support of this, Grunfeld et al, (2006) agrees that “caring for an elderly family member with dementia at home may create a situation of chronic stress, which may adversely affect the caregiver's emotional and physical health”. Although there are rewarding aspects of caregiving, some studies report increased symptoms of depression and anxiety among caregivers (Wagner and lacey, 2004).

It is unanimously agreed that home care is regarded as potentially burdensome, however; according to Grasel (2003) it is necessary to distinguish between contributing factors to the burden that can be measured objectively (for example, the extent to which the care is needed, the degree of financial privation involved) and the assessment of the situation through the eyes of the caregiver concerned.

## **2.9 Perceived challenges on the area of caregiving**

Community caregivers are faced with emotional and physical hurdles. Depression and a feeling of isolation for both the primary family caregiver and the recipient are not uncommon. A positive attitude helps many caregivers push through difficulties with a smile which is truly appreciated by the senior citizens they serve. Also, respite services by a professional caregiver help the family maintain a positive attitude. Working with individuals needs the community caregiver to have patience. Those providing care to HIV/Aids positive patients may face physical, mental or emotional challenges that can be particularly difficult. A caregiver is necessary to offer compassionate and kind care that all patients deserve.

Eliopoulos (2005) defines rehabilitation as the practice of making patients capable of living again. The focus is upon the function rather than the cure. Rehabilitation specialists strive to teach a person how to function at his or her maximal level within the limits imposed by an injury or a physical or mental impairment. It is evident that family members suffer too much burden as primary caregivers because the quantity and quality of the resources and support systems are not always sufficient for nursing care at home (Okamoto, 2007). As the condition of frail older relatives deteriorates over time, they require more care, assistance, and time; many family caregivers are obliged to place their older relatives in institutions (Kong, 2008). When the burden becomes such that the caregiver can no longer cope and must institutionalize the ill family member, it was found that caregivers showed signs of depression, feelings of relief, satisfaction, sadness, loss, and guilt after institutionalization of their frail older relatives (Kong, 2008).

A number of studies have described the challenges experienced by family caregivers within a nursing home setting. According to Dauenhauer (2006), these challenges include the decision to place a loved one in a nursing home being made with little time to contemplate alternative caregiving options, family members' lack of knowledge about nursing homes to make an appropriate decision, financial stress associated with paying for long-term care, fear that nursing home placement may be the "wrong" decision, resentment from the older relative and other family members, relinquishing of primary caregiving duties to a professional staff and difficulty

adapting to a new caregiver role. Further, family caregivers who institutionalize their older relatives often experience guilt associated with the placement, and have symptoms of depression (ibid). Regardless of the burdensome nature of caregiving, nursing home placement is a difficult decision for both the caregiver and the care receiver (Chenier, 2002).

Families also struggle with deciding to place an older relative in a nursing home as it symbolizes their failure as caregivers and often goes against their older relative's wishes (Dauenhauer, 2006). Institutionalization is not only an issue of health and social service burden; it also affects the quality of life and independence of senior citizens. Thus, it is important to determine risk factors for long-term institutional care. So far, in addition to age and female sex, several predictors for institutionalization have been reported. These include dementia, functional and physical disabilities, chronic medical conditions, living alone and social isolation and incontinence. Incontinence is involuntary loss of control of either urine or faeces that interferes with hygiene and health (Matsumoto, 2007).

Many spouses and children give dedicated care to their demented family member for several years, but sooner or later some family caregivers struggle with the decision to move their relative to a nursing home. After nursing home placement, there were significant decreases, in the five domains of caregivers' strain (i.e. physical strain, social constraints, time constraints, interpersonal strain and elderly strain demands) except one domain, the financial domain (Coon, 2009). Family caregivers report less depression when the person with dementia is in an institution than when he or she is being cared for at home (Wagner and Lacey, 2004)

Institutionalization of an elder care recipient is often seen to be a viable strategy for relieving stress. Heston and White (1983), as cited by Dellasega (2008) advised caregiving families for cognitively impaired person that when caring for a demented person becomes intolerably stressful, alternatives must be sought. Most often, placement in a nursing home is the only answer. They indicated that the elderly seem to feel abandoned and useless, due to their lack of input into the surrounding environment. The relatives of the institutionalized individuals especially if it is their parents are never without remorseful feelings.

Nursing and social work are two professions that are extensively involved in HIV services provision. As a social worker, it is stressful to see people dying, just because there is no one who is supporting them emotionally and financially. Personal growth is derived from working with issues related to death and satisfaction is derived from positive relationships with patients and being able to provide support. There are rewards stemming from working with a diverse patient population.

## **2.10 Stigma and discrimination of community caregivers to HIV patients**

According to Baron and Byrne (2002:57), “many patients ask their carers not to disclose to others the nature of their illness when it is HIV related, causing further isolation for the community caregivers and the patient”. Community caregivers themselves sometimes try to keep the status of those in their care a secret for fear of the stigma and discrimination they may suffer, while volunteers in home-based care programmes are often assumed or suspected to be HIV positive themselves (ibid). With the increased availability of anti-retroviral therapy, some stigma and discrimination has declined but it remains quite prevalent (UNAIDS, 2008).

UNAIDS (2008) further states that perceived and actual stigma means that carers fail to access the available support for those in their care and miss out on important information and advice on HIV and AIDS. If clients cannot be sure that their status will be kept confidential by formal healthcare workers or caregivers are mandated to disclose their client’s HIV status, distrust may build between people living with HIV, caregivers and the formal health sector (ibid). This could deter people from being tested and in the long run they will develop AIDS-related illnesses resulting in communities continuing to carry the burden of care. HIV related stigma can also be found where there is limited understanding of the nature, cause and transmission of HIV (Crewe, 2002:446 - 454).

## **2.11 Home and community based care (HCBC) integrated plan**

The Home and Community Based Care (HCBC) programme responds to the needs of people, individuals, families and communities to access holistic and comprehensive services nearest home. This encourages participation and a return to

the tradition of care-giving in community life, which strengthens mutual aid opportunities and social responsibility.

Home based care services focus on the family as a whole and can be classified into preventative, promotive, therapeutic, rehabilitative, long-term maintenance and palliative care categories.

Research has shown that terminally ill people prefer to pass on in familiar environments. According to the report of Department of Health, December 2001, it reported that the family members of those who died at home or in a hospice felt less guilty than relatives of patients who died in hospital. Hospitals may provide good medical care and hygienic conditions, but often isolate patients from their families.

By its very nature, the home based and community based care (HCBC) programme provides psychosocial care and support to those infected with and affected by HIV and AIDS and other chronic conditions, and enables individuals, communities and families to access services closest to their homes. It can also be an entry point to other services.

The focus of social development interventions in the home and community based care (HCBC) programme is on the social impact of HIV and AIDS, namely the burden of chronic diseases that hamper the normal functioning and development of individuals, families and communities.

These interventions also involve:

- strengthening the capacity of families and communities to deal with the consequences of HIV and ADS and other chronic conditions
- tackling poverty
- creating an environment conducive to the provision of care and support, and
- A safe environment for the care and support of orphans and older persons, as well as the youth (those who are vulnerable) and people with disabilities.

The services offered by the HCBC programme primarily focuses on sustaining quality of life. This requires a concerted effort by government and civil society alike.

The emergence of HIV and AIDS increased the prevalence of opportunistic diseases, overcrowded and understaffed hospitals, public and private health care



costs and deaths that contribute to the escalating number of orphans, vulnerable children and households headed by children. The resultant increase in indigent individuals and communities has also seen a return to traditional home and community based care initiatives.

In South Africa, the HIV and AIDS epidemic progressed at an astonishing pace and has taken a devastating toll on human lives. The condition has escalated to levels similar to other chronic conditions such as hypertension and diabetes. Treatment poses challenges, such as a lack of capacity and the required measures for Government to respond efficiently to the needs of HIV-positive adults and children, as well as those living with other chronic conditions. While medication is a priority, other challenges, such as access to treatment, are compounded by the neglect of psychosocial-related issues and sustained care.

The stigma attached to and discrimination against people living with HIV and AIDS (PLHIV) hampers the effective implementation of preventative care and support programmes. Consequently, indulgence in risky social behaviour continues to fuel the high rate of HIV infections, while it deters PLHIV from adhering to prescribed treatment. This, in turn, often results in a resistance to prescribed drugs and a high mortality rate.

It has become evident that HIV and AIDS erode traditional family and community support structures and systems, disintegrate families and lead to dysfunctional communities. In addition, the burden on the welfare system to cope with disability grants to PLHIV and other chronic conditions, although on a temporary basis, is significant. Initially, organisations established to care for and support people affected by and infected with HIV and AIDS were mostly based on the hospice and community-driven care models.

An HCBC programme remains one of the best alternative ways of caring for and supporting people infected with and affected by HIV and AIDS and other conditions. This includes orphans and vulnerable children, child-headed households, the youth, older persons and people with disabilities. Generally, however, HCBC services are provided by organisations funded mainly by Government, and therefore have a limited source of funding and while None Profit Organisation (NPO's) have access to other sources of funding, such as national and international donor organisations, as well as the private sector and religious bodies, the availability of these funds is often

not sustainable. The community caregivers play a vital role in assisting the clients from disadvantages background and those who cannot access services.

They build the capacity of individuals, families and communities to enable them to deal effectively with the consequences of HIV and AIDS and other chronic conditions, minimize the risk of HIV transmission within communities by maintaining sustained levels of care and support, increase awareness about the prevention of infection and re-infection through the promotion of a holistic approach to a healthy lifestyle, empower communities to care for their own health and emotional and social wellbeing by strengthening the capacity of community caregivers and the management of Home and Community Based Care (HCBC) organisations.

HIV and AIDS and other chronic conditions affect individuals as well as their families, friends and the wider community. People living with HIV and AIDS and other chronic conditions should be given opportunities to develop their capabilities, skills and support networks, Government departments (2000).

## **2.12 Types of community caregivers**

There are two types of community caregivers: home health aides and personal care aides.

### **2.12.1 Home health Aides**

Home health aides work for agencies that receive government funding and must comply with government standards and regulations. They also keep records of their activities, which are open to inspection by government agents. These types of community caregivers also receive specific training, they perform basic medical duties, such as monitoring vital signs or giving medication to their patients.

Home health aides make a remarkable difference in the lives of the sick, disabled and elderly. They provide them with personal skills such as dressing and bathing. They also help them look after their homes and train them to be more independent. They also arrange leisure activities and transportation for clients so they can remain engaged in their communities. Working as a home health aides does not always mean working in a private home. Their clients may reside in retirement communities, assisted living facilities, group homes, or other transitional housing. Regardless of

where they work, most home health aides care for a single client at a time, but may have several clients to visit in one day. These community caregivers are supervised by a patient's healthcare provider and sometimes by a patient's family member.

Home health workers typically have a high school diploma. They need to meet government standards. They are required to pass a competency test to show they meet minimum job requirements. Some states require formal post-secondary training for all community caregivers, which is available from vocational schools, elder care programmes and community colleges. Lastly, voluntary certification is available from the National Association for Home Care and Hospice, which can make caregiving jobs easier to find.

### **2.12.2 Personal care aides**

Personal care aides are also known as home makers, personal attendants or companions. They work for agencies that are not funded by the government. They help with daily tasks, such as shopping, bathing, dressing and taking clients for medical appointments. Formal education is not necessary for these caregivers because they typically learn their skills on the job and from more experienced workers or supervisors.

## **2.13 Theoretical framework of caregiving**

The perception of caregiving has long been postulated in a wide range of theories. Caregiving has an important bearing on psychological functioning. This section looks at the conceptual interpretations of caregiving; the concepts are Exchange theory and modernisation theory of caregiving. These concepts explain caring and its implications and they enhance the understanding of the factors that influence different patterns of caregiving (Goldberg, 2016). Exchange theory is a micro-level theory and modernization theory is a macro-level theory; they provide alternative perspectives for understanding the phenomenon of caregiving (Saroukhani and Gharib, 2013).

### **2.13.1 Exchange theory and caregiving**

Exchange theory is useful when explaining the relationship between the caregiver

and the care recipient (Saroukhani and Gharib, 2013). Exchange theory originated with the work of Homans (2005). It explains how factors influence patterns of interaction and relationship between two actors. Based on the tenets of exchange theory, a relationship between the caregiver and care recipient depends on the capacity of the actors to mutually reward one another with something of value. For example, in an exchange relationship, resources that may be used to reward others may include assistance with personal grooming, housework, money, information, affection, approval, labor, compliance, or various types of material support (Saroukhani and Gharib, 2013). If one actor has a lower capacity to reward the other person in a relationship, then the actor with less exchange resources is assumed to be more dependent in the relationship (Durant & Christian, 2006).

Dowd (1980) cited by Durant and Christian (2006) state that exchange theory was among the first to be used in social gerontology. Dowd (ibid) advanced the argument that aging affects exchange relationship in a sense that people desire to profit from social interaction. The profit consists of a perception that the reward coming from the interchange outweighs the cost. Saroukhani and Gharib (2013) maintains that, “the ability to profit from an exchange depends on the exchange resources that the actors bring to exchange. When resources are reasonably equal, then a mutually satisfying interdependency may emerge. However, if one of the actors has substantially fewer exchange resources, then the actor’s ability to profit from the exchange can be sharply restricted. In other phases, actors attempt to maximize their rewards and minimize their cost in their interactions with others”. Exchange relations that get too far out of balance may lead to unstable relationships that could have negative consequences for both the caregiver and care recipient, such as stress, role strain, feelings of guilt and feelings of dependency.

According to Homans (2011), one of the most common patterns of exchange relationships occurs within the context of the family, where adult children are the caregivers for aging parents. Exchange relationships among family members develop at different intervals over the life courses of the parties involved and may be shaped in different ways by various factors including resources, social class, gender, ethnicity, personality, health, residence and the duration, intensity and quality of the relationship between the caregiver and the care recipient.

Durant and Christian (2006) argue that the task of caregivers in the modern world has evolved immensely into becoming a job. It is where caregivers may devote some of their resources for the exchange of major resources, which is money. In that regard, it is obvious that from the side of caregivers, they would have fewer resources to contribute into the relationship between them and the caregiving recipient.

In the view of exchange theory, when one actor has fewer resources to exchange, the opportunity of achieving from the relationship is restricted. Therefore, if caregiving would be seen as the only means of getting monetary gains, there is a possibility that their relationship with caregiving recipients will be unbalanced. The opinion of exchange theory in an unstable relationship has repercussions such as stress and role strain. Although caregivers may devote more resources than the caregiving recipients, the consequences remain the same (Durant & Christian, 2006).

### **2.13.2 Modernization theory and caregiving**

Saroukhani and Gharib (2013) state that, unlike exchange theory which is a micro-level theory, modernization theory is a macro-level theory which deals with the influence of societal changes on social roles, relationships, and resources, which may directly or indirectly influence caregiving. Modernization theory proposes that the processes that cause society to change from a traditional social system to a modern industrial social system may change the status that older people occupy in society and the esteem afforded to them individually as members of a social category (Durant & Christian, 2006).

Societal changes may have positive and negative consequences for individuals and groups in society. Simmons (2008), an anthropologist, conducted one of the earliest studies of the effects of modernization using a cross-cultural group of seventy one (71) societies. Simmons (ibid) concluded that in relatively stable agrarian societies, elders usually occupy positions of honour, favour, and power, mainly due to the norms of seniority rights (ibid). However, when the rate of changes increases, older people lose their advantaged status. From a sociological perspective, Cottrell (2005) view modernisation as “creating conditions that guide more complex forms of

organization, including the family. In such families, older members lose many of their dominant roles in making family decisions and performing family functions". Accordingly, family roles shift from ascribed to achieved roles and statuses, which influence the distribution of power and resources and pattern of relationships among family members (Goldberg, 2016). The lower status of older people in the family tends to limit their roles and choices, reduce their authority, and thus make them more dependent on other family members. It is in this way that caregivers become relevant modern alternative to caregiving between adults and children. Caregivers may also influence caregiving exchange relationships between adult children and their aging parents.

According to Goldberg (2016), some analysts argue that some theorists and researchers emphasize the negative effects of modernisation and place less emphasis on the positive effects. Not-with-standing the negative effects resulting from technological advancements, modernisation has raised the level of education, increased the level of income, vastly improved health and medical technology, and created many scientific discoveries and breakthroughs, which have significantly increased the quantity and quality of life (ibid).

Other scholars argue that modernisation is a continuing and uneven process, thus making it difficult to determine the degree or direct source of the societal influences. Moreover, changes in values, attitudes, beliefs, knowledge, and practices create a complex process that may precede modernization at initial point, which raises the old age question. However, we do know that at some point, advanced technology does change the ways in which we live and make decisions that influence family life and functioning, including caregiving relationships between adult children and their elderly parents. Accordingly, modernisation theory can be useful in explaining how aging and treatment of older persons as a social category have changed within a given period of time (Durant and Christian, 2006). This theory may also be useful in explaining why and how certain societal changes influence the formation and dynamics of caregiving to the elderly population (ibid).

## **2.14 Elderly care in South Africa**

The global population is ageing and many governments have made the care of older people a policy priority. There is a pressing need therefore for nurses and carers to work in health services for older people. Ageing is becoming a concern in South Africa. Since the 1980s the provision of housing for the elderly in South Africa has been regarded as a joint venture of the public and private sector. However, the Department of Social Development in 1997 proposed the phasing out of all state-funded homes for the aged by the year 2000 (Kotze, 2009) . Nevertheless, there are luncheon clubs which older persons are advised to join so that they can share ideas, experiences and keep themselves busy. As a social worker, the researcher has seen that older persons enjoy being together especially because of the role played by many government departments such as Department of Sports which organised soccer and other games that suit them .

It is generally thought that being old and black (and poor) compounds the likelihood of placement into particular types of institutions. Many researchers have noted the relationship between the type of facility in which an elderly person may be institutionalized and the status attributes of that elderly individual (Kart, 2001). The poorest elderly are more likely to be placed in public facilities which generally provide an inferior form of care. Not all elderly persons have access to a range of available institutional settings. Some investigators have expressed concern about the differential availability of institutional settings for elderly blacks and whites (Kart, 2001).

## **2.15 Strategies for effective caregiving**

Effective caregiving takes knowledge of disease, people, and human behavior. It looks at the interpersonal relations and with caregiving techniques. The community caregivers must flexible in routine and approaches and be aware of what works today may fail tomorrow.

### **2.15.1 The Needs of Working Caregivers**

Little systematic research has been conducted explicitly on the needs of working caregivers. Rather, policies and services have been developed primarily based on

the needs inferred from the results of researchers and anecdotal reports from working caregivers concerning their situations and needs (Neal and Wagner, 2002). One need is for flexibility, particularly in the scheduling of work hours. A second set of needs centres on information and assistance, an area in which the aging network has considerable expertise (Neal and Wagner, 2002). A third area of need is that for emotional support and a fourth is for other tangible assistance, such as with health insurance paperwork (ibid).

### **2.15.2 Flexibility**

Working caregivers routinely note the importance of both flexible work hours and being able to take unscheduled time off when needed to handle caregiving responsibilities (Neal and Wagner, 2002). A recent study of working sandwiched generation couples found that couples who felt they had work schedule flexibility experienced less work-family conflict. Work schedule flexibility and other work-based supports offered by employers to their employed caregivers have generally been perceived quite positively on the part of the caregivers. This, in turn, has led to increased loyalty and satisfaction with those employers. Community caregivers assist with much of the care provided by families including household chores and providing and cooking food, as well as performing more clinical tasks such as administering pain relief or medication. They may also make referrals for more professional medical help, Karasz A.D (2003).

### **2.15.3 Information and assistance**

The needs of working caregivers vary according to the care situation and the needs of the care recipient. Regardless, however, just as their non-employed counterparts, working caregivers need information on the community services that are available to support the needs of the elderly (Neal and Wagner, 2002). Most caregivers of the elderly have had little or no previous experience either with providing care to an elderly or with negotiating the aging services system. Thus, information about caregiving, health conditions, and where to turn for help is a critical need for working caregivers. Because of the complexity of many elders' health care situations, working caregivers, like other caregivers, can find it difficult to know even what is



needed, let alone decide which service approach is best for their elderly (Neal and Wagner, 2002). Professional expertise can be invaluable for assessing the elderly's needs, providing referrals and advice, determining eligibility and payment options, and packaging together the needed services.

#### **2.15.4 Emotional support**

Emotional support for working caregivers can come in the form of support from co-workers and supervisors at the workplace, support from other family members, and support from friends (Neal and Wagner, 2002). Lower levels of family-related supervisor support were associated with higher levels of work-family conflict. Similarly, a less supportive workplace culture was associated with work-family conflict. Support groups allow those facing the difficult task of daily caregiving to benefit from interaction and support from other people in similar situations. A support group work toward mutual problem-solving, coping, dealing with grief and sharing information. Some communities have a network of established support group, others may have few.

Finding a support group to share stories with, seek advice from and simply have available to listen to you on a regular basis can help lower your caregiver stress and alleviate the health risks that caregivers face. Emotional support Include the person with HIV in social engagements outside of the household. This may be difficult if your loved one becomes bed-bound, but it's worth the effort. Just as other members of the household are involved in events and activities outside the home, make sure the person with HIV has the opportunity to share in these connections. Social activities don't have to be complicated, try inviting your loved one to do something as simple as watching television or listening to music with a group. Even if it's just to a friend's house in the neighborhood, a change of scenery can be uplifting and invigorating for your loved one when he or she is feeling down Karasz A.D (2003).

#### **2.15.5 Other tangible assistance**

Working caregivers need help with legal, financial, and health insurance matters and paperwork associated with these. Helping an elderly manage paperwork associated with his or her medical care is a daunting task. Similarly, securing and completing

the legal forms for durable power of attorney, wills, reverse mortgages, and the like can be frustrating and time-consuming ( Neal and Wagner, 2002; Wagner, 2000). Trained volunteers in local agencies can also provide help. Providing access to elder law professionals through workshops or through a listing of such professionals would be of great benefit to caregivers because they can arrange seminars whereby they discuss educational topics. (Neal and Wagner, 2002; Wagner, 2000)

## **2.16 Summary**

Daily tasks as a community caregiver are becoming more difficult to perform. Until the recipients realize that they already depend on community caregivers, daily tasks for a community caregiver will continue to be difficult. Caregivers fall into two broad categories: caregivers working for pay who are part of the formal health care sector (e.g. homecare workers) and unpaid "informal" caregivers (usually family members) (Grunfeld, 2006; Wagner and Lacey, 2004). Formal homecare workers are often those that fill that gap between family support and patient needs. Prompted by a concern about the emotional and physical costs of being a caregiver, many researchers have investigated the link between caregiving for the elderly and the mental and physical health of caregivers (Koerner, 2009). Their studies have repeatedly found a significant association between caregiving and heightened emotional or mental health problems. For example, we know that caregivers are at increased risk of depression when compared to non-caregivers. They have elevated levels of hostility and anxiety, as well as concerns over insufficient time, loss of self, and missed social opportunities (Koerner, 2009). Studies also provide evidence that caregivers' physical health can be compromised (ibid).

Although negative outcomes such as depression, burden, and health risks remain an important focus in caregiving research, a growing body of literature acknowledges the potential rewarding and positive outcomes of the caregiving experience (Koerner, 2009). Caregiving benefits or gains include feeling more useful and needed, learning new skills and adding meaning to one's sense of self (e.g. they may also include gaining a sense of fulfillment for meeting a duty or obligation and enjoyment) derived from caregiving itself or from companionship with the care recipient (Koerner, 2009). A recent mixed-methods study of caregivers revealed that the vast majority could

describe one or more positive aspects of caregiving. Caregiving satisfaction represents the perceived subjective gains and rewards, and the experience of personal growth that occurs as a result of providing care.

## **CHAPTER THREE**

### **3. RESEARCH METHODOLOGY**

#### **3.1 Introduction**

In this chapter, research design, target population, sampling and sampling size, research tool, pilot study and ethical consideration are discussed. The goal of the research study was to look at the experiences of community caregivers at *eMondlo Township* clinics, in order to determine what they come across when carrying out their daily duties. Research methodology considers and explains the logic behind research methods and techniques (Welman, et al 2005:01). It is the strategy of enquiry, which moves from the underlying assumptions to research design and data collection (Thomas, 2010). Although there are other distinctions in the research mode, the most common classification of research methods is into qualitative and quantitative. At one level, qualitative and quantitative refer to distinctions about the nature of knowledge on how one understands the world and the ultimate purpose of the research (ibid).

#### **3.2 Research design**

Research design is a detailed outline of how an investigation will take place. A research design will typically include how data is to be collected, what instruments will be employed, how the instruments will be used and the intended means for analyzing data collected. It focuses on the end-product of the study that is being planned and what kind of result are aimed at. It looked on the logic of research (Roller 2009:45)

The research study adopted qualitative research methods, but have also integrated elements of a quantitative approach. In qualitative research approach the information is gathered by actually talking to people and observing their behavior. This was done particularly to get holistic views on the experiences of the community caregivers. Qualitative research methods are used to gain insight into people's attitudes, behaviour, values systems, concerns and motivations. The design enables the researcher to collect the data in the field at the site where participants experience

the issue or problem under investigation. The data was collected in the field where respondents were required to provide information based on their experiences when performing their duties. The qualitative researcher is expected to feel very personally involved in every step of the research process, because every consideration and decision has to be based entirely on personal grounds.

Qualitative research methods are designed to help researchers understand people and what they say and do. They are designed to help researchers understand the social and cultural contexts within which people live. According to Myers (2013), one of the key benefits of qualitative research is that it allows a researcher to see and understands the context within which decisions and actions take place. It is often the case that human decisions and actions can only be understood in context, it is the context that helps to explain why someone acted as they did, and this context (or multiple contexts) is best understood by talking to people (ibid). Qualitative researchers thus contend that it is virtually impossible to understand why someone did something or why something happened in an organization without talking to people about it. They also argue that if you want to understand people's motivations, their reasons, their actions, and the context for their beliefs and actions in an in-depth way, qualitative research is best (Creswell, 2009:181).

### **3.3 Motivation for qualitative research methods**

In qualitative research methods, researchers collect data in the field where participants experience the issue or problem under investigation. In this study the researcher collected data in the field where respondents were invited to participate in the research. Usually in qualitative research approach the information is gathered by talking to people and seeing the behaviour within their context. It also regulates face to face interaction over time (Creswell, 2009:181). This is possible in the case where the researcher goes to the place where respondents are.

In addition, qualitative research is fundamentally interpretive. This means that the researcher makes an interpretation of the data. This includes developing a description of an individual or setting, analyzing data for themes and categories, and finally making an interpretation or drawing conclusions about its personal and

theoretical meaning (Creswell, 2003:182).

### **3.3.1 Advantages of qualitative methods**

One advantage of qualitative research method is that it uses open-ended questions; and probing gives participants the opportunity to respond in their own words, rather than forcing them to choose from fixed responses. Open-ended questions have the ability to evoke responses that are meaningful and culturally salient to the participant, unanticipated by the researcher, rich and explanatory in nature (Mangal and Mangal, 2013).

Qualitative method is helpful not only in giving rich explanations of complex phenomena, but in creating or evolving theories or conceptual bases, and in proposing hypotheses to clarify the phenomena. Besides, the value of the qualitative research is in the validity of the received information. People are minutely interviewed so as to obtain data that would be taken as correct and believable reports of their opinions and experiences.

Qualitative method allows the researcher the flexibility to explore initial participant responses, that is, to ask why or how (Mangal and Mangal, 2013). The researcher must listen carefully to what participants say, engage with them according to their individual personalities and styles, and use “probes” to encourage them to elaborate on their answers (ibid).

### **3.3.2 Disadvantages of qualitative methods**

Qualitative research method scope is limited due to in-depth, comprehensive data gathering approaches required. The very subjectivity of the inquiry leads to difficulties in establishing the reliability and validity of the approaches and information. It is very difficult to prevent or detect researcher induced bias and the major disadvantage of qualitative research is that a small group of interviewed individuals cannot be taken as representative.

Qualitative research is not understood well by classical researchers; since it demands the researcher to listen carefully to what participants say, engage with them according to their individual personalities and styles, and use “probes” to

encourage them to elaborate on their answers (Mangal and Mangal, 2013). Qualitative research can be difficult and expensive and require a lot of time to perform. It must be carefully planned to ensure that there is complete selection of sample and correct designation of control groups. Qualitative researchers do not always underpin the understanding of multi-dimensional pictures of the research study conducted.

### **3.4 Population of the study**

Neuman (2006:224) defines population as a large pool of cases of elements, such as persons, groups of people, organizations' written documents, symbolic messages and social actions under investigation. In that large group, a researcher draws a sample from which results would be generalized. Population is any group that is the subject of research interest (Naude, 2002:46). The population for this study was community caregivers working at *eMondlo* Township. The population was targeted to provide the study with relevant responses regarding the normal experience in the work of being a community caregiver for HIV/AIDS patients. Those caregivers were employed by the Department of Health, and the researcher consulted the Department of Health to gain access to community caregivers for data collection. The size of the population was sixty five community caregivers working under the Department of Health.

### **3.5 Data collection procedure**

Data collection is the process of gathering and measuring information on variables of interest, in an established systematic fashion that enables one to answer stated research questions, test hypothesis, and evaluate outcomes (Mouton, 2001). The data collection component of research is common to all fields of study including physical and social science, humanities and business (ibid). While methods vary by discipline, the emphasis on ensuring accurate and honest collection remains the same (Most et al 2003:103).

### **3.5.1 The importance of ensuring accurate and appropriate data collection.**

Regardless of the field of study or preference for defining data (quantitative, qualitative), accurate data collection is essential to maintaining the integrity of research (Mouton, 2001). “Both the selection of appropriate data collection instruments (existing, modified, or newly developed) and clearly delineated instructions for their correct use reduce the likelihood of errors occurring” (Most et al 2003:103).

### **3.5.2. Sampling procedures**

Sampling is the act, process, or technique of selecting suitable respondents or a representative part of a population for the purpose of determining parameters or characteristics of the whole population. The study used random sampling technique to select the participants. Punch (2005:102) asserts that in random selection each element in the population has an equal chance to be chosen.

The township of *eMondlo* has three public health clinics namely *Thembumusa*, *Bhekumthetho* and *Mondlo 2*. *Thembumusa* has twenty four (24) community caregivers; *Bhekumthetho* has sixteen (16) community caregivers and *eMondlo 2* has twenty five (25). In total, there are 65 community caregivers working within *eMondlo* Township, and the study targeted twenty four (24). The study used 37% of population to represent the population.

Out of the total of 65 community caregivers 24 were purposively selected in order to represent all three sites (Grinell &Unrau, 2014:309). Purposive sampling is a sampling technique in which researcher relies on his or her own judgment when choosing members of population to participate in the study. It is a non-probability sampling method and it occurs when elements selected for the sample are chosen by the judgment of the researcher. Eight (8) respondents were selected proportionally from three different public health clinics at *eMondlo* Township.

### **3.5.3 Data collection**

The study used face to face interview as a tool to collect data. Punch (2005:172)



asserts that this type of an interview is a non-standardised, open-ended, in-depth interview, and is used as a way of understanding the complex behaviour of people.

Face to face interview it is also a data collection method when the interviewer directly communicates with the respondents in accordance with the prepared questionnaire. This method enables to acquire factual information, participants evaluations, attitudes, preferences and other information coming out during the conversation with the respondent. Thus face to face interview method ensures the quality of the obtained data and increase the response rate.

This approach is useful when the study is interested in discovering the respondents' personal experiences about a particular phenomenon. In this study respondents provided the researcher with their own insight on the community caregivers' working conditions at *eMondlo* Township. The researcher prepared a set of questions that were asked to each respondent. The General Health Questionnaire (GHQ) was adopted for the study including the use of interviews for the purpose of collecting primary data from the participants.

#### **3.5.4The General Health Questionnaire**

The General Health Questionnaire (GHQ) is a widely used measure for psychological well-being with demonstrable validity and reliability. It asks respondents about their recent experiences of symptoms known to be indicative of anxiety and depression, social dysfunction, and loss of confidence and self-esteem. It will help in achieving on how community caregivers are affected by their work , asses the work related conditions affects community caregivers providing services to persons living with HIV and AIDS at *eMondlo* community.

#### **3.6 Data analysis and interpretation**

Struwig and Stead (2007:169) assert that "data analysis methods enable the researcher to organise and bring meaning to the large amount of data". Content analysis was used in this study. In content analysis themes were extracted from the responses of the respondents. In doing data analysis using content analysis approach, themes were extracted through coding, elaborating, interpreting and then checking the data (Terre Blanche, Durrheim, & Painter, 2006:322). Qualitative data may take the form of interview transcripts collected from research participants or

other identified texts that reflect experientially the topic of the study. The goal of qualitative data is to gain insight, explore the depth and complexity inherent in the phenomenon. It examines the uniqueness of individuals lived situation and each person has their own reality. Data interpretation follows by means of synthesizing responses provided by the respondents, thus the researcher is able to attach meaning to the findings.

### **3.7 Ethical consideration**

Ethical consideration is an accumulative of values principles that address questions of what is good or bad in humans affairs (McDonald, M. (2003). Ethical aspects of the study have been effectively addressed as proposed by Yilma (2013) and McDonald (2003) in the following manner: The researcher sent a letter requesting the Department of Health to conduct the study. The identity of individuals from whom information was obtained was kept strictly confidential. No information revealing the identity of any individual was included in the final report or in any other communication prepared in the course of the study.

Participants were informed that the data collected from them would be treated with the highest level of confidentiality; they were also informed about their right to withdraw participation in the study, should they feel uncomfortable at any time. Permission to record interviews was also requested and obtained from respondents. The participants signed a consent form before participating in the study.

The researcher ensured that confidentiality and anonymity was maintained throughout. Respondents have participated in the study voluntarily and have been fully informed about the aims and objectives of the study, the questionnaires did not contain any degrading, discriminating or any other unacceptable language that could be offensive to any members of the sample group, the questionnaire has been designed to collect information directly related to the research questions, and no private or personal questions were asked from respondents (Yilma, 2013). Permission to conduct the research study was obtained from the University of Zululand's Ethical Committee and from the Department of Social Work as well as Department of Health under Zululand District.

### **3.8 Summary**

The chapter has outlined the research paradigm, research methodologies, and strategies and design used in the study, including procedures, participants, data collection tools and analysis method (Thomas, 2010). The research design for this study was a qualitative design that helps researchers to understand people with their social and cultural context and what they want to say. Further it also briefly described the several stages involved in the design and development processes of the research in this study (ibid).

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## **CHAPTER FOUR**

### **4. THE HISTORICAL BACKGROUND OF *EMONDLLO* TOWNSHIP**

#### **4.1 Introduction**

This chapter deals with the history of *EMondlo* Township near Vryheid in KwaZulu-Natal. It looks at the demographic profile of the population. It explains the various programmes, which are rendered by various institutions in trying to assist those who are affected and infected by HIV/AIDS. This chapter is also aiming at determining the availability of external support to families and community caregivers who are affected by the HIV/AIDS pandemic.

#### **4.2 The historical background of *eMondlo* township and its origin under Abaqulusi Local Municipality**

In 1963, *eMondlo* Township near Vryheid in KwaZulu- Natal was established as an exclusively African settlement through a process of forced removals. Sanctioned by the Group Areas Act of 1950 and other apartheid laws, black residents, many of whom had freehold title to their land and residences, were forcibly removed from the so-called 'black spots' of KwaBhanya (Besterspruit), Kingsley, the Khambule mission, as well as farms surrounding Vryheid. They were taken to an undeveloped site near the *Mondlo* mountain, approximately 28 kilometres outside Vryheid within the boundaries of the KwaZulu homeland and left to establish a new community.

From the start, the government invested little in infrastructure and the people had to struggle with inadequate housing, sanitation and water supply and the absence of normal community amenities such as medical and recreational facilities, affordable transport and policing. In addition, there were few work or business opportunities in *eMondlo* for many years and many residents were forced into the migrant labour system. Political strife from the 1980s further limited the development of *eMondlo* Township.

Background of Forced Removals and Apartheid in Vryheid When the National Party under the leadership of DF Malan came into power in 1948, racism was already

institutionalized in South Africa. The whites only parliament enacted a series of racially discriminatory laws to enforce separate development that negatively affected the non-white population. In 1950 parliament passed the notorious Group Areas Act, which meant to force the South African population to live in separate residential areas according to their racial classification (whites, African, Indians and Coloured). Africans were also intended to reside separately according to cultural or tribal designation in specified tribal reserves, e.g. the amaZulu to KwaZulu, amaXhosa and amaMpondo to Transkei and Ciskei and amaSwazi to KwaNgwane. By 1970, the grand apartheid plan was for these reserves to become independent black states, from which the influx of any black people required to work in white South Africa would be strictly controlled and regulated.

Today, *eMondlo* faces a serious backlog in infrastructure development. Even after almost twenty years of democracy and limited restitution through the finalization of land claims, the lack of opportunity and investment has led to high levels of crime and general poverty. The causes of all these problems can be directly traced to the destruction and forced removal of stable communities and the failures of apartheid social engineering.

Abaqulusi Local Municipality is located in the Northern part of KwaZulu-Natal province and forms part of the Zululand District Municipality (Abaqulusi Local Municipality IDP, 2015/2016). It is named after the Abaqulusi, a Zulu clan whose descendants live in the vicinities of Vryheid, Utrecht, eDumbe, and eNgoje. Abaqulusi Municipality comprises of many settlements, both rural and urban, with Vryheid being its main urban settlement (Wikipedia, 2016). Other areas of interest that fall within the boundaries of Abaqulusi also include Louwsburg, *eMondlo*, *Hlobane* and *Bhekuzulu*. It is estimated at 4185 km<sup>2</sup> in extent making it one of the largest in the province with a population of approximately plus or minus 211 060, according to census 2011 (Abaqulusi Local Municipality IDP, 2015/2016). The population of Abaqulusi has been growing steadily since 2001, from 2001 to 2011 the population of the municipality increased by 20 041 people to the current 211 060 people (ibid). It at present constitutes approximately 30% of the Zululand District Municipality and is one of the five local municipalities that make up Zululand District Municipality (ibid). The other four local municipalities that make up the Zululand family include *eDumbe*, *oPhongolo*, *Nongoma* and *Ulundi*. The municipality is also

characterized as the main hub for the district and is also very strategically positioned, sharing its border with all of the four local municipalities within the district. The Abaqulusi municipality comprises of twenty two wards, making it one of the largest local municipality within KwaZulu-Natal. It consist of twenty two ward councillors, twenty two party representatives councilors and seven traditional authorities, totaling forty four councillors. The Abaqulusi Municipality includes the following main nodal points, eMondlo has tribal area of Hlahlindlela south-west of Vryheid town. Number of rural settlement areas around Brakfontein between eMondlo and Vryheid in the western part of the Municipal area (Abaqulusi Local Municipality IDP, 2015/2016).

## 4.3 Demographic characteristics

### 4.3.1 Population density

The Abaqulusi Integrated development plan (IDP) Review 2013/14 notes the disparity in various estimations regarding the population size for the municipal area (Abaqulusi Local Municipality IDP, 2015/2016).

Table 1 below drawn from Stats SA (2011) shows AbaQulusi is population statistics within the context of the Zululand district. The Zululand district is estimated to have grown at an average of 0, 30% from 780 069 to 803 575 between 2001 and 2012. The population of the Abaqulusi municipal area is estimated to have grown at 1, 0% since 2001 to 211 066 in 2012. The Abaqulusi municipal area accounts for 30% of the Zululand district population.

### 4.3.2. Population Estimates

<b>Municipality Population</b>	<b>2001</b>	<b>2011</b>	<b>Population Growth</b>
AbaQulusi	191019	211066	1.00
Nongoma	198443	194908	-0.18
Ulundi	188585	188317	-0.01
EDumbe	82241	82053	-0.02
EPhongola	119781	127238	0.60
Zululand	780069	803575	0.30

**Source: Stats SA (2011)**

In terms of geographical distribution, the population of the Abaqulusi local Municipal area is quite skewed with *Hlahlindlela* and *eMondlo* accounting for 61% of the population followed by Vryheid (15%) and *Khambi* (9%).

**4.4 Traditional authorities**

The municipality has seven traditional authorities as detailed below:

TRADITIONAL AUTHORITY	INKOSI	WARD
Ekhambi	Nkosi BM Zulu	3
EMathongeni	Nkosi TA Zulu	4
EMmpangisweni	Nkosi JV Zondo	4
EMsiyane	Nkosi KM Xulu	5
Egodeni	Ndlunkulu M. Mthethwa	7
Hlahlindlela	Nkosi SW Mdlalose	21
Othaka	Nkosi J Mdlalose	22

**4.4.1 Structure of the Abaqulusi Local Municipality**

Municipal Manager

Strategic Executive Director Corporate	Chief Financial Officer	Strategic Executive Director Technical Services	Strategic Executive Director Development Planning	Strategic Executive Director Community Services
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## **4.5 Social development analysis broad based community needs**

### **4.5.1 Education**

There are a total of 133 schools in the Municipal area. The average number of pupils per teacher is lower than the acceptable national ratio of 40:1 for primary schools and only slightly higher than the 35:1 for secondary schools with the ratios for urban areas being much more favourable than those of the rural areas where in some instance the pupil: teacher ratio can be as high as 56:1 (Abaqulusi Local Municipality IDP, 2015/2016).

This, together with higher pupil: ratio classroom ratios indicate a shortage of teachers and inadequate school facilities in most of the rural areas within AbaQulusi Municipality (ibid). It must also be noted that pupils in rural farms travel long distances to access educational facilities which results to problems in the children physic and their interest to education (ibid). This matter has been raised with the MEC for Education in the province. The Mthashana College (technical) offers tertiary courses on a part-time or full-time basis to about 650 students. It should also be noted that Vryheid plays an important regional educational function and draws pupils form the whole sub-region.

### **4.5.2 Health**

The AbaQulusi Municipality has one public hospital and 12 clinics servicing the population of 224 546 people (Abaqulusi Local Municipality IDP, 2015/2016). An application of the planning standard (5000 households per clinic) for the provision of clinics reveals a backlog of about 26 clinics for AbaQulusi Municipality area of jurisdiction (Data Source: ZDM Health Sector Plan (2004). Other hospitals found within the area include Hlobane Hospital which has about 30 beds, Mountain View Hospital, Siloah Lutheran Hospital (ibid).



### **4.5.3 Safe and Security**

#### **4.5.3.1 Police Services**

There are six police stations located within AbaQulusi Municipality area of jurisdiction, namely:

- Vryheid
- eMondlo
- Gluckstadt
- Louwsburg
- Driefontein
- Ngome

The need to improve police visibility and strengthen community based policing initiatives was identified in the Representative Forum meeting as one of the key issues that requires immediate attention. Although statistical information pertaining to the crime rate within the area could not be obtained, it is certain that crime is a major concern within the area.

### **4.6 Nation building & social cohesion**

According to Abaqulusi Local Municipality IDP (2015/2016), the following activities within AbaQulusi Municipal Area contribute towards nation building and social cohesion.

- Local Mayoral Cup
- District Mayoral Cup
- Sports Activities
- Umkhosi wezintombi
- Reed Dance (for Young Zulu Maidens)
- Umbele wethu
- Indigenous Games
- Mayfair (Annual)

## **4.7 Community development**

AbaQulusi Municipality takes pride in itself by not only rendering basic services to its citizens but also lay an important role in nurturing the societal fabric through integration with other stakeholders under the banner of Operation Sukuma Sakhe (OSS) (Abaqulusi Local Municipality IDP, 2015/2016). OSS is a unique KwaZulu-Natal initiative that seeks to bring together all government departments and municipalities not on paper only but through real action and immediate impact. The Municipality is fully represented in OSS by amongst others in Local Aids Council, Men's Forums, Religious Formations, *Izintombi* (Virgin Maidens), Disability Forums and many more as will be discussed in the foregoing (ibid).

## **4.8 Youth development**

The municipality has the responsibility of co-ordinating the development and promotion of youth development initiatives, establishment of youth desk and youth structures and implementation of procedures, reporting and upliftment of youth programme.

## **4.9 Development of people with disability**

According to National Disability strategy municipalities are charged with the responsibility to ensure that the playing field is levelled for entry into the job as well as into all municipal programmes (Abaqulusi Local Municipality IDP, 2015/2016). That was the reason the municipality established the Abaqulusi Disability Forum (ADF). The forum works within the municipality population accounts for about 5% of people living with disabilities (ibid). Awareness campaigns amongst community to treat and acknowledge disabled person abilities would be enhanced in the year.

## **4.10 Development of women**

It has been researched that no society thrives where women are not supported and respected. AbaQulusi population studies indicate that its population is comprised highly of women standing at 53% as per the recent Census results (Abaqulusi Local Municipality IDP, 2015/2016). Being an area with more Zulu speaking population its

is known that even culturally women are revered and respected by the population and as such there are specific projects that are sponsored targeting at empowering women like women in agriculture and in establishing co-operatives with a view to growing them .

#### **4.11 People affected by HIV& AIDS**

Dealing with the impact of HIV & AIDS pandemic is beginning to register positive results as AbaQulusi is leading the way in testing and know your status campaigns. The active role played by the Councillors under the Local Aids Council (Abaqulusi Local Municipality IDP, 2015/2016). The Operation Sukuma Sakhe (OSS) task team members also played a very active role in ensuring that the fight is won at local levels under the collaborative strategies like establishing War-rooms at Ward levels. Not all Wards have War-rooms, but by the year 2013/14 more War-rooms were established and were operational.

AbaQulusi supports Education Department in Winter Schools where apart from refining matriculants for the future academically, but also its a platform to capacitate them with real life skills to deal with peer pressure when at tertiary levels and in the work place (Abaqulusi Local Municipality IDP, 2015/2016). Again there is a successful programme targeted at young men and men in general who have not circumcised. Medical Male Circumcision (MMCs) provides participants with an invaluable opportunity to be taught how to behave as real men. This includes how to treat women, good ethical conduct and values (ibid).

#### **4.12 HIV/AIDS support programmes for eMondlo Township**

There are various support systems for community members. Different departments and non-government organizations are involved in assisting families and children who are affected or infected by the disease, HIV/AIDS (van Dyk, 2007). They assist communities by empowering them with different skills and knowledge so that they can be in a position to cope with the stressful situation that they find themselves in. The Departments of Health, Social Development, Education and Agriculture try to assist communities in dealing with the appalling situation that they find themselves in.

#### **4.12.1 Challenges in addressing people who are affected by HIV/AIDS**

The number of individuals infected with HIV/AIDS continues to be a major challenge. HIV/AIDS infections in Abaqulusi grew from 3.97% in 1995 to 19% in 2007 (Wikipedia, 2016). There was a substantial increase (49.89%) in deaths that were due to HIV/AIDS between 1995 and 2007. In 1995, 160 deaths were due to HIV/AIDS and in 2007 there were 2383 HIV/AIDS deaths (ibid). Thus in 2007, 41.13% of all reported deaths were due to HIV/AIDS (Abaqulusi Municipality LED Sector Plan, 2009). The HIV and AIDS prevalence rate for the KwaZulu-Natal province as a whole is estimated at 39% .As a result, without proper nutrition, health care and medicine that is available in developed countries, large numbers of people suffer and die from AIDS-related complications (WHO, 2010). In some areas, the epidemic has left behind many orphans cared for by elderly grandparents. HIV/AIDS also severely retards economic growth by destroying human capital (Integrated development plan review in Abaqulusi local Municipality, 2014).

#### **4.13 Summary**

The area is characterised by social ills which have a past history of neglect. The government of national unity is addressing the problem of unemployment in the area and making sure that services is rendered efficiently in the community since the government invested little in infrastructure and the people had to struggle with inadequate housing, sanitation and water supply and the absence of normal community amenities such as medical and recreational facilities, affordable transport and policing. HIV/AIDS becomes the priority and there are now programmes that are being initiated to alleviate this social problem. This chapter has attempted to give an overview of the history of the *EMondlo Township*.

## CHAPTER FIVE

### Data Analysis

#### 5. Introduction

This chapter focuses on analysis, presentation and interpretation of the collected data. The researcher focused on the work related conditions affecting community caregivers on HIV/AIDS positive people at *eMondlo* Township. The information that is presented in this chapter was obtained from the questionnaires administered to respondents at *eMondlo* clinics which were *Thembumusa*, *Bhekumthetho* and *Mondlo 2*. The researcher interpreted data using content analysis and tables so that figures of the respondents were clearly arranged. The researcher gathered data from 24 respondents consisting of females from three different clinics at *eMondlo* Township. Eight (8) respondents were selected proportionally per public health clinic at *eMondlo* Township.

#### 5.1 Data analysis

Data analysis involves breaking up the data into manageable themes, patterns and trends. The aim of analysis is to determine whether any pattern or trends can be identified or isolated, or to establish themes in the data (Mouton, 2001). Struwig and Stead (2007:169) assert that “data analysis methods enable the researcher to organise and bring meaning to the large amount of data”. Content analysis was used in this study. In content analysis themes were extracted from the responses of the respondents. In doing data analysis using content analysis approach, themes were extracted through coding, elaborating, interpreting and then checking the data (Terre Blanche, Durrheim, & Painter, 2006:322).

### SECTION A

#### 5.2 DATA PRESENTATION

Data presentation refers to the main characteristics of the data set described in an easily understandable manner, referring to the data and indicators disseminated (Terre Blanche, Durrheim, & Painter, 2006:322) . Data presentation includes the description of the dataset disseminated with the main variables covered, the classifications and breakdowns used.

### 5.2.1. Biographical data

The information regarding personal details of the respondents that were required by researcher was as follows: gender, age group, marital status, ethnic group and home language. This data on biographical information was quantitatively analysed.

### 5.2.2 Distribution of data according to gender

**Table 1: Gender Distribution**

<b>GENDER</b>	<b>NUMBER</b>	<b>PERCENTAGE</b>
<b>Females</b>	24	100%
<b>Total</b>	24	100%

Gender distribution in this study was considered to establish the dominant gender among community caregivers. The results as displayed in Table 1 below indicate that 100% of the respondents in this study were females. This indicates that the role of community caregivers continues to be occupied by women as opposed to men. Perhaps this could also be attributed to the role that women play in most families.

### 5.2.3 Distribution of data according to age

**Table 2: Age Distribution**

<b>AGE</b>	<b>NUMBER</b>	<b>PERCENTAGE</b>
<b>35 - 40 years</b>	12	50%
<b>26 - 35 years</b>	10	42%
<b>18 - 25 years</b>	02	8%
<b>Total</b>	24	100%

The researcher wanted to find out how people of different age groups view working conditions that affect community caregivers on HIV/AIDS positive people. The table below demonstrates the responses on the question of age and the distribution of respondents according to their age.

#### 5.2.4. Distribution of data according to marital status

**Table 3: Marital status of the respondents**

MARITAL STATUS	NUMBER	PERCENTAGE
Single	17	71%
Married	06	25%
Widow	01	04%
Divorced	00	00%
Total	24	100%

The question of marital status was asked to find out how people of different marital statuses view working conditions that affect community caregivers on HIV/AIDS positive people. The Table below demonstrates the responses to the question of marital status.

#### 5.2.5. Distribution of data according to ethnic group

**Table: 4 Ethnic group distribution**

ETHNIC GROUP	NUMBER	PERCENTAGE
African	24	100%
Total	24	100%

The question of ethnic group was asked to respondents to find out how people of different ethnic groups view working conditions that affect community caregivers on HIV/AIDS positive people. The table below demonstrates the responses to question of ethnic group.

#### 5.2.6. Distribution of data according to home language

**Table: 5 Home languages of the respondents**

HOME LANGUAGE	NUMBER	PERCENTAGE
IsiZulu	23	96%

<b>English</b>	01	04%
<b>Total</b>	24	100%

The question of home language to respondents was asked in order to establish how people of different languages view working conditions that affect community caregivers on HIV/AIDS positive people. The table above demonstrates the responses to questions of home languages.

## **SECTION B**

### **5.3 Findings of the study**

Data is discussed in terms of themes and sub-themes that emerged in data analysis. The challenges that are experienced by community caregivers are discussed in detail. Themes and sub-themes are as follows:

<b>Themes</b>	<b>Sub-themes</b>
<b>Feelings</b>	<ul style="list-style-type: none"> <li>• Denial</li> <li>• Rage</li> <li>• Fear of disclosure</li> <li>• Stigma</li> <li>• Emotional feelings</li> <li>• Secretive</li> <li>• Rebellion</li> <li>• Openness</li> <li>• Friendliness</li> <li>• Mutual respect</li> </ul>
<b>Relationships</b>	<ul style="list-style-type: none"> <li>• Attachment to community caregivers</li> <li>• Lack of cooperation from families of the patients</li> <li>• Lack of respect from health professionals</li> <li>• Ruined relationships</li> <li>• Relationships and acceptance</li> <li>• Improved confidentiality</li> </ul>



<b>Empowerment</b>	<ul style="list-style-type: none"> <li>• Empowering community caregivers with skills</li> <li>• Improving service conditions</li> <li>• Usefulness</li> <li>• Training families of patients about community caregiving</li> <li>• Social workers at local clinics</li> <li>• Future developments</li> </ul>
<b>Challenges</b>	<ul style="list-style-type: none"> <li>• Lack of substantial food</li> <li>• Lack of cooperation from patients</li> <li>• Travelling long distances on foot</li> <li>• Revised salaries for community caregivers</li> <li>• Fear to contract disease</li> <li>• One stop centre</li> <li>• Alienation and lack of family support</li> <li>• Shortage of resources and finances</li> <li>• Lack of debriefing</li> <li>• Treatment default</li> </ul>

### 5.3.1 Theme 1 – Feelings

The following sub-themes are discussed namely denial, rage, fear to disclose their status, stigma, emotional, secretive, rebellion, openness, friendliness and mutual respect.

#### (a) Denial

Respondents indicated that most of the patients they dealt with were in denial of their status. Generally, being in denial has over the years been noted to be a factor that hinders the treatment of many patients who have HIV/AIDS. As patients are in denial of their status, treatment is started at a later stage when the virus has normally fully developed. In such instances community caregivers also struggle to convince patients to start with HIV/AIDS treatment. A study by Homans (2005) concurs with this finding that most HIV patients are in denial.

Whilst some patients are in denial, others do not know their HIV status and do not even want to go for testing. Those who know their status but are in denial have not

disclosed their status. Mostly men do not want to accept help especially from caregivers and it gets to a state where they become angry and violent towards community caregivers. Because they are in denial and have not accepted their status, community caregivers serve as a reminder to them that they are actually HIV positive. They do not want to be reminded of that fact and thus poses a danger to their health not only due to the lack of awareness on how to help themselves but also that they will not get help immediately to avoid worsening their state of health. One respondent quoted her patient saying “I am not HIV positive, how come my partner is HIV negative”.

### **(b) Rage**

Respondents indicated that they often encounter rage from HIV/AIDS patients, mainly due to their HIV status. Respondents further indicated that some patients did not want them as community caregivers to visit their families. One of the respondents reported that her client said, “I went to various hospitals, prophets and even traditional healers trying to save my life but all my efforts were rewarded badly because people were gossiping about my health.” The family could even go to an extent of hiding people who are sick especially if they did not accept community caregivers (Beardslee *et al.*, 2003:112). According to Sherman (2000:151), the emotional stress on caregivers of all ages is significant. Children without adult supervision, having experienced the grief of losing their parents, face the responsibility of feeding and clothing their siblings which put them at risk of exploitation and harm (UNAIDS, 2008).

### **(c) Fear of disclosure**

Some of the patients have the fear of disclosing their status. The stigma around HIV/AIDS haunts them. This hinders the opportunity of getting help quicker and prolonging their lives. These patients usually battle with bereavement overload, fear of more exposure to HIV, and difficulty to cope with their own stigmatisation and confidentiality issues (Beardslee *et al.*, 2003:112). One respondent mentioned that her client said According to UNAIDS (2008), perceived and actual stigma means that carers fail to access the available support for those in their care and miss out on important information and advice on HIV and AIDS. If clients cannot be sure that their status will be kept confidential by formal healthcare workers or caregivers are

mandated to disclose their client's HIV status, distrust may build between people living with HIV, caregivers and the formal health sector (ibid). This could deter people from being tested and in the long run they will develop AIDS-related illnesses resulting in communities continuing to carry the burden of care. HIV related stigma can also be found where there is limited understanding of the nature, cause and transmission of HIV (Crewe, 2002). One respondent mentioned that her client said "Why must I tell you my status? You want to drink tea with your family discussing my medical history."

#### **(d) Stigma**

The participants of this study saw family and community stigma as an obstacle in the provision of healthcare. Adebayo (2004:54) stated that caregivers observe poverty, stigmatisation and discrimination that people living with HIV and AIDS must endure. Herek et al. (1999:2) mentioned that the stigma surrounding HIV/AIDS had resulted in HIV positive people being hated and seen as outcasts. Nobody wanted to be near them and many felt it almost impossible to take care of them. The stigma surrounding HIV/AIDS also resulted in those infected being denied life insurance, which could serve as a guarantee to buy an apartment or a house (Arber & Knipe, 2001:1532). HIV and AIDS also compromised the life of those it infects, resulting in illness, loss of their houses and disempowerment. "I am reluctant to readily welcome community caregivers because of late disclosure and lack of knowledge by family members regarding caring of their loved ones and are labelled by being HIV positive". The exchange theory and caregiving works together because it explains social changes and stability as a process of negotiated exchanges between parties.

#### **(e) Emotional feelings**

Community caregivers' work and their personal lives were affected. One respondent reported: "At times I felt angry or resentful towards the person that I am caring for, even though they knew it was irrational". Caregiving work has many frustrations especially on handling additional responsibilities. Moreover, community caregivers get stressed and fear what will happen in the future if the patient's illness progresses because caring for an ailing is just too stressful, often triggering damaging emotions that cannot only undermine community caregiver's good work but harm their health as well. In the view of Baum and Posluszny (2008:137-163), caregivers were generally

not trained adequately to offer HIV-related counselling and other health services. Caregivers largely felt unsupported by their employers, family and friends.

#### **(f) Secretive**

In this study seventy percent (70%) of the respondents reported that most of their patients found it difficult to disclose their status. One respondent reported that “Disclosure is difficult for some patients because sometimes they would not have told their families, friends or partners”. Patients would sometimes like to first deal with their own emotions before telling other people. This process is important and should be allowed to take its course. The community caregiver and other support group members would be needed when the patient decides to tell their family and friends as they would need a lot of support. It is always best to ask the individual the kind of support they might need as their patient. The carer must always ensure that the members have had pre-test and post-test counselling and ensure that the member gets counselling and ongoing support (Beardslee et al., 2003:112).

#### **(g) Rebellion**

Participants reported that their patients did not trust them as community caregivers. Patients sometimes think that community caregivers would share their status with partners, families, friends, colleagues and other health workers. This could be an incredibly tough and emotional experience, and something which people without HIV would probably not fully comprehend (Pozzy, 2016) . Nevertheless, disclosure is vitally important and can lead to safer sexual practices and may encourage partners to get tested. It can also be the first call for support from friends and family and a way of discovering support groups and networks of people living with HIV. However, due to the high levels of stigmatisation and wide misunderstanding of the disease, disclosure of an HIV-positive status is difficult for some people, perhaps harder than informing people about infections of other viruses or diseases (Castro & Farmer, 2005:53). One respondent stated that her patient said “I would not tell you my health history because you will tell the whole world about my condition.”

#### **(h) Openness**

Respondents indicated that some patients were more open about their health status, and did not hide anything. It was easy to assist such clients as there were no limitations. One respondent mentioned the following “If the patients were more open,

it would be easier to assist and communicate with them.” In the case of being open it was easier to address patients’ spiritual concerns, to work with family and friends and to resolve their unfinished business (Karasz et al., 2003).

### **(i) Friendliness**

Almost all participants reported that the relationship with their patients was positive. They were open about treating patients’ matters with confidentiality. One respondent indicated that “We talk about important and sensitive topics at a time and place that was relaxed and conducive for open communication”. Community caregivers also learned the best way of communicating with their patients. One of the most important guides they gave to their patients was that if they wanted to discuss uncomfortable issues, they should feel free to talk. However, patients were left with the responsibility of coming up with appropriate timing. The patient should also be left with decisions on what feelings to share, when, how, and with whom. By not pressurising the patient with an issue, they are allowed to retain control of their life (Karasz et al., 2003).

### **(j) Mutual respect**

Respondents reported that their patients were always taken seriously and treated respectfully. Caregivers expected patients to also respect them and see them for what they are doing to assist patients. Furthermore, mutual respect was demonstrated when both patients and community caregivers understood what was happening in the relationship. Mutual respect between patients and caregivers can increase patients’ feelings of security to work together to solve the problem at hand. One participant mentioned “There were situations where the community caregiver touches the patient and listens to what the patient has to say, which means that the patient experiences the empathy of the caregiver”. This strengthens the patient’s power and thus provides an opportunity to grow as a person while they experience that the caregiver takes them seriously and really want to assist them.

This mutuality can demonstrate the patient’s own power and thus provide an opportunity to grow as a person. Confirmation is where patients know that they are dependent on their community caregivers; therefore, it becomes even more important for caregivers to be seen and to take their patients seriously. Community

caregivers listen and help patients in difficult life situations. They must believe that the patient can smile even in life's darkest moments.

### **5.3.2 Theme 2 – Relationships**

The following sub-themes will be discussed here, namely attachment to community caregivers, lack of cooperation from families of the patients, lack of respect from health professionals, ruined relationship, relationship depends on acceptance and improved confidentiality.

#### **(a) Attachment to community caregivers**

Participants indicated that at times some of the patients would become attached to them as their caregivers based on dependence in critical periods of life (Barker, 2014: 30). Developing attachment towards someone who is providing assistance is a normal state of affairs. These findings were synonymous to the exchange theory by Homans (2005), which explains the factors that influence the relations between two persons. The theory states that tenets of the relationship should meet each other half way in order for the relationship to be balanced and to minimize tensions between the parties. Since the HIV/AIDS patients have developed attachment towards community caregivers, it can thus be assumed that their relationship is somewhat balanced, or perhaps the community caregivers are fully committed at having a working relationship with their patients, hence they have developed attachment.

Due to the lack of family support in helping most HIV positive patients, their quality of life deteriorates because of not having food to eat, breach in the manner in which medication should be taken, unable to bath themselves and clean the place where they live. When caregivers come and help with these chores they get attached to them because it gives them new hope and feel loved because of the support they receive. One participant mentioned "I heard some of my patients saying to each other what shall we do without our caregivers, please so come and visit me even if you know I'm feeling better and do not need daily assistance".

#### **(b) Lack of cooperation from families of the patients**

Findings indicated that caregivers were inadequately assisted by relatives, friends, neighbours, private individuals, grassroots traditional and political leaders, and other

service delivery networks like Non-Profit Organisations (NPOs). The sentiment below was unanimously echoed by the majority of caregivers. “Relatives and family members help here and there, but very little.” This indicated the possibility that caregivers could get overwhelmed, making it difficult to cope with their daily chores. Family members and relatives often neglect their duty towards ill family members and leave caregiving in the hands of caregivers alone. Respondents demonstrated the pain and agony a caregiver undergoes while left to carry out caregiving alone. One respondent mentioned “Due to long distances I have to cover when conducting my routine home visits I sometimes take over 2 weeks to come back to the same patient but upon my next visit I find that no family member has offered to help with anything”. The exchange theory is useful in when explaining the relationship between the caregiver and the care recipient (Saroukhani & Gharib, 2013). Its explain how factors patterns of interaction and relationship between two actors.

Participants mentioned the antagonism, resistance and poor cooperation by family members when caregiving contradicts the family belief system. This was especially evident in refusing to continue with care in the absence of the caregiver and instead of being caring, loving and patient, participants observed that family members sometimes abused the patient emotionally and physically. Community caregivers felt overwhelmed and frustrated, especially when they had to take time off and leave their patients unattended for a few days (Farran et al., 2004:47). Caregivers sometimes provide care to patients without knowing their HIV status. They are only informed after a long period of exposure to the sick, which can be regarded as a violation of human rights (Ndaba-Mbatha & Seloilwe, 2000:222).

### **(c) Lack of respect from health professionals**

The relationship between community caregivers and the clinics was highlighted as a problem, with community caregivers reporting poor relationships with health professionals such as nurses. One respondent mentioned “Community caregivers were treated inferior and not valued by professional nurses”. It has been indicated that there is a lack of respect from health professionals towards community caregivers. An important determination of success for community caregivers is the relationship between community caregivers and formal health sector (Boyatzis, 1998). Unfortunately, the community caregivers felt lack of support from the formal health sector. The line of reporting for community caregivers were unclear and

inconsistent because it was indicated that even though they reported to both the community caregivers' supervisors and the community caregivers' facilitators there was still nothing done regarding the patient's status.

Community caregivers stated that government officials, especially nurses, did not treat patients well. Respondents reported that government officials mislead their patients by giving unnecessary information and by disrespecting them. The patients ended up discouraged to attend their local clinic for their health. By so doing, the community caregivers got the challenge of counseling the patients then refer them to a local clinic again. Some staff members took a long time before providing assistance to the patients; even caregivers got little help from health professionals in managing their duties and emotional demands of care giving. Respondents stated that they got more disappointments from health care personnel such as nurses and doctors. This shows lack of care, guidance and quality of caregiving. This has negative results in caregiving productivity and coping in general.

#### **(d) Ruined relationships**

Community caregivers' relationship with their patients varies in different ways and for different reasons. One participant stated "Sometimes our relationship with the clients is not good because patients do not listen to the instructions they give them". The community caregivers reported that they sometimes end up being aggressive towards their patients due to limited time and because they found it stressful to repeat the same thing. That causes caregivers not always to be trusted and patients disliking them. Heston and White (1983), as cited by Dellasega (2008) advised caregivers in these cases to look for alternatives such as swapping patients and caregivers.

#### **(e) Relationships and acceptance**

Participants reported that for caregivers to be accepted by the patients, patients needed to accept themselves first as they were living with HIV/AIDS. Unfortunately, it is not straightforward for patients to disclose their HIV positive status, and methods of disclosure will vary by context and relationship. Revealing such personal information should occur only when the person concerned feels comfortable to do so. Some people may nonetheless prefer to inform others through, or with the help of a third party such as a doctor. Seeking advice from other HIV-positive people who



have disclosed their status could also be useful, as long as it is remembered that everyone's experience and resulting reactions would differ. Patients should be assessed and evaluated from time to time to see where they are in terms of accepting their status.

Community caregivers have to assist patients to be in control of their situation, such as the kind of support they would need, the person that would give them that support, the difficulties they would encounter at certain points and the positive aspects that would make them cope better. In fact, discussing these issues with patients could help them be in touch with their feelings (Dellasega, 2008). One respondent mentioned that her patient once said to her "We have been together for such a long time and you never disappoint me". Community caregivers have to look at things that would help them to be in control of their status, i.e. the kind of support they would need; the person that would give them that support; the difficulties they would encounter at certain points and things that would make them feel better (Norman, 2007).

In fact, discussing these issues with patients could help them be in touch with their feelings. Participants reported that for caregivers to be accepted by the patients, patients needed to accept themselves first as they were living with HIV/AIDS. Unfortunately, it is not straightforward for patients to disclose their HIV positive status, and methods of disclosure will vary by context and relationship. Revealing such personal information should occur only when the person concerned feels comfortable to do so. Some people may nonetheless prefer to inform others through, or with the help of a third party such as a doctor. Seeking advice from other HIV-positive people who have disclosed their status could also be useful, as long as it is remembered that everyone's experience and resulting reactions would differ. Patients should be assessed and evaluated from time to time to see where they are in terms of accepting their status.

#### **(f) Improved confidentiality**

Respondents in this study reported that they maintained confidentiality with their clients. One respondent mentioned that "As community caregiver I safeguard all confidential information entrusted to me and protect the privacy of my patients". Confidentiality is paramount in the caregiving process, because the community and

patients believe that everyone has the right to their private life. Confidentiality is also based on the principle that community caregivers respect a patient's autonomy as it is believed that people are capable of making their own decisions. Confidentiality towards the status of community caregivers' patients is essential in the relationship and cannot be stressed enough. This is one of their ethics that need to be implemented when assuming their duties.

### **5.3.3 Theme 3 – Empowerment**

The following sub-themes will be discussed in this theme, namely treatment default, empowering community caregivers with skills, improving conditions of service, usefulness, training families of patients about community caregiving, social workers from the Department of Health at local clinics and future developments.

#### **(a) Empowering community caregivers with skills**

Seventy percent of respondents emphasized that skills training must be provided for them. Acquired skills could assist community caregivers to create a caring environment in their working place and help them to enhance their psychosocial well-being, whilst building, managing and sustaining practical support systems (Karasz et al., 2003). Strengthening community caregivers competences and confidence would improve their mastery. Community caregivers with high levels of mastery have more positive responses in providing care because they perceive themselves as able to meet care demands. One participant mentioned that "Training now and again could assist us by not being stressed because it is where we could debrief as colleagues with our daily challenges".

#### **(b) Improving service conditions**

Respondents stated that they have problems that affect them already for a long time but were not attended to. One participant mentioned that "We as caregivers should be given petty cash for travelling and for small immediate needs of patients". They complained that they were tired of using their own money to buy food for patients and proposed that the government must at least provide them with two vehicles so that they could perform their duties as expected by the Department of Health. Community caregivers further suggested that they be provided with cell phones rather than relying on landline telephones to communicate with their patients and their offices. This would improve their daily tasks and diminish work stress and

frustration.

### **(c) Usefulness**

Participants reported that the home based care programme is crucial within the community. This programme provides care services to ensure that the basic needs of people living with HIV/AIDS were met. One participant said “I would say if they were no community caregivers thousands of people would have already passed away – this programme is essential to care for communities in the grip of HIV/AIDS”. The home based care programme offers care, counselling and support to people living with HIV/AIDS, provides and distributes condoms, addressing the needs of child headed households, linking families and community caregivers with programmes that address poverty, providing food parcels and food supplements, establishing support groups and promotes information sharing (Karasz et al., 2003).

### **(d) Training families of patients about community caregiving**

Respondents reported that the relationship between community caregivers and the family members of their patients could be improved. One participant mentioned “The training of family members is important because a primary caregiver is the person who takes primary responsibility for someone who cannot take care of themselves, that will help family members to understand our duties because they sometimes do not trust us”. Training of family members reduces worries among family members when the community caregivers conduct home visits. Respondents indicated that the training might be done by a family member, a trained professional or another individual. Depending on culture, there might be various members of the family engaged in giving care. Respondents proposed more TV shows that would educate the whole of South Africa about community caregiving. In that case, issues of discrimination of patients with HIV/AIDS within their families could be decreased. My findings are being supported by the modernisation theory that is defined as the process that causes the society to change from traditional social system to a modern industrial social system.

### **(e) Social workers at local clinics**

In this study, respondents reported that the Department of Health needed to hire social workers at *eMondlo* Township for the three local clinics. Respondents indicated that the patients needed counselling services from time to time, to help

them cope with their life circumstances. Some patients had many maladies. Others were affected emotionally, and when it came to people living with HIV/AIDS, their social roots counted a lot. Social workers can assist individual patients to find resources for dealing with their problems. Patients, who do not accept their status of being HIV positive, need social workers to render services to them. Social workers can assist the chronically ill patients adjust to life at the clinic or hospital. One participant said, “Social workers within these three local clinics are a need because social workers are the heart and soul of the community”, the exchange theory supports that within the caregiving. Social workers at local clinics can play a vital role because there will be an easier and professional way of communicating with social workers from the Department of social Development to visit the cases reported at local clinics, because the respondents affirmed that social workers took a long time to visit cases even if the case was urgent. The community caregivers ended up frustrated on the condition of their patients when they were not attended.

#### **(f) Future developments**

All of the participants requested a salary increment for the stressful job they do. One participant said “As human beings working for the community we would like to move with the times in whatever we are doing”. Participants pleaded for a more flexible system of distribution of medication and vitamin supplements, to teach family members and neighbours about how to care for patients, such as to give bed-baths, how to lift a patient, mouth care and other basic nursing skills, food preparation for patients, arrangements for transportation of patients, and the provision of human contact in the case of isolated persons as modernisation theory strategies. Participants emphasized the importance of the early arrival of resources.

#### **5.3.4 Theme 4 - Challenges**

The following sub-themes will be discussed here, namely lack of substantial food, lack of cooperation from patients, travelling long distance on foot, revised salary for community caregivers, fear to contract disease, one stop centre, alienation and lack of family support, shortage of resources and inadequate nutrition, lack of debriefing, finance and treatment default.

##### **(a) Lack of substantial food**

Some patients ended up isolating themselves and not taking their treatment in the

prescribed manner because they lack money and the correct food. Financial problems such as the loss of income and other financial support lead to lack of food and clothing and the inability to cope with the high cost of living (UNAIDS, 2000:12).

The respondents indicated that “due to insufficient income, most patients lacked substantial food in support of their bodies even though the government provides a grant for them to obtain food”. For these patients, quantity is preferred over quality, and therefore that grant ended up serving to buy other necessities and to support family members. The other most common problem quoted by one respondent was that “In most cases, community caregivers conducted home visits without supplementary food”. It can be regarded as demoralising to keep a patient on ARV’s without the proper supplementary food.

#### **(b) Lack of cooperation from patients**

Most patients do not handle the burden of being HIV positive well. One participant said “Patients isolate themselves and do not want to accept help from community caregivers”. Patients think there is no life after being diagnosed HIV positive. Even those patients that accept help find it difficult to fully cooperate with the objectives of the programme. When patients feel ill they do not take their medication and some pregnant women with HIV do not attend clinic sessions. From time to time patients close their door and do not want assistance from community caregivers because they say that nothing the caregivers do will change their status.

#### **(c) Travelling long distances on foot**

Travelling long distances on foot was one of the biggest problems mentioned by community caregivers. This was due to a large area that they have to cover on foot walking from one patient to another. One participant had the following to say “By the time I reached the patient’s home, I was already tired because in rural areas the households were scattered and there was no transport to move between households”. Community caregivers reported exhaustion of having to walk long distances to visit patients and were not getting a travelling allowance (Grunfeld et al., 2006). Modernisation theory consent that the change is essential through the transition from traditional society to a modern.

#### **(d) Revised salaries for community caregivers**

Participants reported that there was inadequate motivation and incentives for them.

One participant stated that “I was not exposed to any motivation what so ever in my caregiving work”. The programme was de-motivating, demoralizing, lacked incentives, recognition, rewards and any strategy to motivate them as community caregivers. This had the effect of making coping immensely challenging. The respondents reported that lack of incentives was the reason why caregiving did not attract young women and men. The findings support the modernisation theory that the community caregivers also needed fringe benefits like other government employees (Grunfeld et al., 2006).

#### **(e) Fear to contract disease**

The participants indicated that one of the potential risks associated with caring for HIV and AIDS clients is the increased probability of contracting the disease through exposure. In caregiving, there is commitment of time and effort that may be made at a high price to one's self. Caregivers believe that there has to be recognition of some sort by the patient, the family and the organisers of the programme (Phaladze, 2003). One participant said “There is too much contact with body fluids and the risk of transmission of infection is high”. Body fluids are infectious and caregivers are dealing on a daily basis with these discharges (Uys & Cameron, 2003:129). Patients are in need of total basic care including bathing, changing of linen, wound dressing and feeding.

#### **(f) One stop centre**

Participants concurred that a one stop centre would assist the community and patients that could not be reached by any programmes in the past. Getting information and services from the government was difficult because of the frustration of being sent from place to place and office to office without getting any help. One respondent said that “Such a service centre is an all in one setting that render different services for our community and that could help the community to know where and how they could get assistance”. This led to despondency and a lack of faith in the government to provide effective services. It was worse in rural areas where distances are vast and travelling to urban centres to get services and information is expensive. It was for this reason that Thusong Service Centres were identified as the main way of implementing development communication (ibid).

They could offer various services that communities could use to better their lives.

Government departments and other sectors offer information and services at the Thusong Service Centres. However, these differ from centre to centre according to community needs. Community caregivers reported that the types of services that patients could find at one stop centre include the following (Thusong Service Centre, 2016):

- Government services such as applications for identity documents, passports, death and birth certificates, pensions, welfare grants, unemployment insurance, information on issues such as health, government structures and organisations, labour issues, citizen rights, education and contact information.
- Telecommunication Services such as, gateway portal, computers, internet, e-mail, Information Terminals (PITs). This helps communities use technology to better their lives.
- Education and skills development training services such as: computer training, Adult Basic Education Training (ABET), opening a business, sewing and art.
- Partnership services such as: commercial and community services which include community banking, craft shops, women's clubs, food production programmes, etc.
- Thusong services also educate the community about health issues such as HIV/AIDS.

**(g) Alienation and lack of family support**

Respondents reported that at times the families of their patients were discriminative which further impacted on the way they were supposed to offer caring service to their patients. The study by Baum and Posluszny (2008) found that caregivers largely feel that their friends, employers and families are not supportive of their occupation. This could be worse if the family of the patient is also not supportive towards caregivers. Baum and Posluszny (2008) further stated that it must be understood that caregiving work is among the most stressful occupations especially when it involves HIV/AIDS care. If therefore, community caregivers continue to feel alienated by the families of their patients as well as their own families and friends, it is likely that their caregiving work would become even more stressful and drop-out of the programme can be expected. As a result, when community caregivers (CCG's) were conducting their

daily routine at their homes such as cleaning the house, bathing them, cooking for them, receive treatment on their behalf at clinics, they found some patients living in a bad state. In fact, caregivers' visitation was the only time they received comfort and love.

#### **(h) Shortage of resources and finances**

Shortage of resources was one of the major problems identified by respondents. It interferes with community caregivers' daily duties, in a sense that they are not able to assist patients as they want to because of the shortage of resources (Grunfeld et al., 2006). Some caregivers added the following: "We have to carry basic materials such as hand gloves, sanitary towels, and food parcels when conducting home visits" Even worse one participant said that "Basic material and resources are mostly lacking and not available on time, meaning that we have to conduct our duties without these basic necessities". Respondents stated that "Perhaps it all boils down to financial constraints and the administrative system regarding access and distribution of health services". The other most common problem quoted by the respondent was that in most cases, community caregivers conducted home visits without supplementary food. The demands inherent in the caregiving work results in many caregivers experiencing tension, which lead to burnout, misery and other psychological problems (Anderson, 2010). Formal and informal caregivers often experience tension because the nature of their work is common in many respects. Community caregivers are at risk of being depressed, of having elevated levels of hostility and anxiety as well as concerns over insufficient time, loss of self-esteem and missed social opportunities (Koerner, 2009). The modernisation theory supports the changes to should occur more often as to improve service delivery from community caregivers.

#### **(i) Lack of debriefing**

Community caregivers indicated that there was a lack of debriefing sessions, whereas community caregivers experienced work overload and interpersonal conflict over a period of time. One respondent said "We are particularly vulnerable to burnout, when looking at our work load and the conditions we work under". The supervisors of the community caregivers are even failing to establish support groups to facilitate training, the expression and discussion of feelings and the provision of



health care and counselling to community caregivers themselves.

#### **(j) Treatment default**

A number of reasons for defaulting from treatment programmes have been hypothesized. These include cost, transport, waiting time, stigma, family pressures, religious beliefs and illness (Murray & Roura, 2009). Respondents indicated that their patients defaulted from treatment simply because of family pressure and stigma surrounding HIV/AIDS. One participant mentioned “There is a lack of family support and HIV/AIDS awareness”. Disclosing their status was one of the problems which lead them not to get support from their families. Sometimes no one in the household is prepared to assist and remind the patient to take his/her medication at the set times. It is further stated that some patients have to walk long distances to get their ARV’s because they do not have money for transport. This also leads to default on their treatment. Male patients were in resistance of taking ARVS treatment simple because they thought they could overcome anything that comes their way. Respondents further stated that male patients accused their girlfriend of infecting them; they pushed the blame and ended up not taking their treatment timeously.

### **5.4 Summary**

Although the community caregivers care for the people living with HIV/AIDS whereas there is no training or counseling that they have been exposed to. Patients give community caregivers hard time when executing their duties, which need to be attended to. The work that community caregivers do requires them to be mentally and physically fit because they also had to walk long distances to help their patients. This drained them physically and they ended up having little time to spend with their own families. Because most community caregivers were very passionate about their work, at times they had to use their own money to assist patients with transportation to clinics to fetch treatment and they also provided them with food so that they do not default in taking their treatment. Respondents indicated that there is a lack of substantial food, lack of cooperation from clients as well as their family members and they have to travel long distance by foot when conducting home visits.

Respondents further reported that they felt positive about doing caregiving work, where they helped people who were unable to help themselves. Community

caregivers further admitted that they were proud of helping people at their lowest level despite all the challenges they encounters in their daily activities. All the caregivers requested salary increments for their development within the caregiving programme. Participants stated that they are doing a variety of tasks without much support, supervision and motivation from outside. The stress associated with caregiving is too much and even worsened by the sporadic unavailability, lack and shortage of resources. The unavailability of transport results in the fact that caregivers had to travel long distances by foot, thus wasting time and ending up not giving adequate care to patients. Both the people living with HIV/AIDS and the community caregiver need to be trained on coping skills.

This chapter has presented, analysed and interpreted the data that was gathered.

## **CHAPTER SIX**

### **6. Findings, recommendations and conclusion**

#### **6.1 Introduction**

The purpose of this chapter is to summarize research findings and recommendations. The aim of the study was to assess the work related conditions that affect community caregivers of people with HIV/AIDS at *eMondlo* Township. The recommendations would serve as guidelines to assist the Department of Health on what could be done to assist community caregivers regarding their challenges. This chapter also draws conclusions on the study that was undertaken. The brief summary on the research is presented and the objectives of the study are re-stated.

#### **6.2 Re-stating the objectives**

The objectives of the study were:

1. To establish how community caregivers were affected by their work related conditions.
2. To explore how community caregivers felt about their work related conditions.
3. To assess the work related conditions that affected community caregivers at *eMondlo* Township.
4. To outline work related consequences experienced by community caregivers.

#### **6.3 Findings per objectives of the study**

##### **6.3.1 To establish how community caregivers are affected by their work related conditions.**

The work that community caregivers did required them to be mentally and physically fit because they also had to walk long distances to help their patients. This drained them physically and they ended up having little time to spend with their families. Because most community caregivers were very passionate about their work, at times they had to use their own money to assist patients with transportation to clinics to fetch treatment and they also provided them with food so that they did not default in taking their treatment. Moreover, being supported by the exchange theory

community caregivers are likely to develop a feeling of discontentment with governmental processes including the misleading or ever changing health messages about their roles as community caregivers (Sherman, 2000:151).

In addition to these changes, there was a shortage of resources because health officials were changing the way things were being done.

### **6.3.2 To explore how community caregivers feel about their work related conditions.**

The results clearly indicate that community caregivers sometimes work in extremely difficult circumstances and require support from their employers (Baum & Posluszny, 2008 and van Dyk, 2007). One respondent indicated that “Caregiving was a calling for me, it was what I am passionate about”. Caregiving was the only job they knew. Respondents reported that they felt happy about caregiving work, where they helped people who were unable to help themselves. Community caregivers further admitted that they were proud of helping people at their lowest level despite all the challenges they encountered when they assumed their duties. Participants further reported that they were very happy to help those who were less fortunate. Baronet (2003) believes that caregiving has benefits including the feeling of being useful, needed, learning modern skills and adding meaning to one’s sense of self. The other benefits are the sense of fulfillment for meeting a duty and enjoyment derived from caregiving itself (Koerner, 2009).

### **6.3.3 To assess the work related conditions that affect community caregivers at eMondlo Township.**

Family members had passed on the duty to care for their loved ones solely to the community caregivers. This had a negative effect because the patients also needed support from family members and the recovery process could be a quick and easy journey if there is good coordination between community caregivers and the families of the patients.

Respondents also mentioned that there was little support from the health officials, especially in instances where there were no ARVs. Health officials made community caregivers wait in queues with their patients, which delayed them from getting help quickly so they could move on to see the other patients.

Respondents emphasized that they were faced with a huge challenge of the shortage of resources. This made it very difficult for them to offer adequate care to patients living with HIV/AIDS. Another challenge that the respondents reported was that there was a great cost associated with their work because community caregivers in *eMondlo* Township had a large area to cover. They had to use their own money for transport. To some extent, the community caregivers used their own hard earned money to transport patients in order to fetch treatment from clinics.

The participants further reported that they also had the challenge with patients who were stubborn, especially male ones who were ignorant about taking their treatment in a prescribed manner. Some patients did not even want to disclose their status to community caregivers which made it difficult for community caregivers to assist them accordingly.

In addition, respondents stated that their patients had anger, which means when they got their results about being HIV positive, proper counselling was not done because patients kept on blaming their previous partners. Other patients were in denial of their status. Generally, denial has over the years been noted to be a factor that hinders the treatment of many patients who have HIV/AIDS. There was also a lack of family support. According to Baum and Posluszny (1999:137-163), caregivers are generally not trained adequately to offer HIV-related counselling and other health services. Caregivers largely felt unsupported by their employers, family and friends (van Dyk, 2007). There was also a shortage of ongoing seminars or workshops to retrain community caregivers so that they remain up to date with latest information on the caregiving field. They also did not have a space where they could sit and talk about the challenges they were facing in the work place as community caregivers.

#### **6.3.4 To outline work related consequences experienced by community caregivers**

The demands inherent in the caregiving work results in many caregivers experiencing tension, which leads to burnout, misery and other psychological problems (Anderson, 2010). The stress associated with caregiving was too much and it was even worse because they also had to deal with the shortage of resources.

Caregivers had to travel long distances and ended up not giving adequate care. This left most community caregivers feeling discontent and useless, because they had not fulfilled their duties to their satisfaction. They were not gaining a sense of fulfillment for meeting a duty and were not deriving enjoyment from caregiving itself (Koerner, 2009). As depression sets in, community caregivers are also at risk of elevated levels of hostility and anxiety as well as concerns over insufficient time, loss of selfhood and missed social opportunities when compared to non-community caregivers (Koerner, 2009; Eliopoulos, 2009).

## **6.4 Recommendations of the study**

6.4.1 Admittedly, in relation with the modernization theory the community caregivers love what they do and are passionate about it, but there is a great need to review their salary structure so as to help them keep up with the high standards of living in the current settings.

6.4.2 Because *eMondlo* Township area is too large and wide, there is a great need to increase the number of community caregivers. This could prove to be cost effective in terms of transport and less area to cover from patient to patient. This also means there will be more patients to check upon in a day and give adequate care at all times.

6.4.3 There is a need for more workshops and seminars for continuous learning and development to help community caregivers learn more about how to provide adequate care to people living with HIV/AIDS. They would also get the latest information and any changes in their field and would also refresh their knowledge.

6.4.4 Caregivers would benefit from more debriefing sessions on how to cope with challenges they come across when performing their duties and how to balance their work and their personal lives.

6.4.5 Transport for community caregivers needs to improve. It is recommended that at least once in a month, community caregivers be transported with a nurse for those

identified individuals who are not able to go to clinics so they could give them treatment. Nurses could also assist in giving workshops to the family members on how to support their loved ones living with HIV/AIDS.

## **6.5 Future recommendations**

Future researchers interested in a similar topic could look at the following:

6.5.1 The manner in which salaries could be structured in the future as to fully accommodate community caregivers taking into consideration the challenges they face.

6.5.2 The relationship between community caregivers and health officials, which will help community caregivers in that they would not have to wait in queues with their patients waiting for health professionals to attend them. The time they wait could be used to help other patients.

6.5.3 Looking at the department's initiative to send community caregivers with a nurse to check their patients at least once a month. That would help patients not to travel especially if their condition is worsening.

6.5.4 Looking at how the government departments ensure the availability of resources to community caregivers so that they could be fully effective in their work.

6.5.5 Carrying a study that investigates community caregivers' employers about their awareness on the challenges faced by community caregivers. The study could also look at the strategies for assisting community caregivers.

6.5.6 The study could look broadly at how the Department of Health as a whole interacts with the employees at lower levels and check how community caregivers along with other health professionals improve in taking care of the patients.

## **6.6 Conclusion**

The study was undertaken to outline work-related conditions affecting community caregivers of HIV/AIDS people at *eMondlo* Township. Findings show that there is a gap between community caregivers and their employer. For example, the level of communication is not equal in that community caregivers do not have a platform where they could express their feelings about caregiving work to their employer. The researcher hopes that some of the challenges reported would be sorted since the Department of Health would be issued a copy of a dissertation document when the research is completed. Furthermore, all appropriate ethical issues were taken into consideration when the researcher was conducting the study, such as gaining written informed consent from all participants, no coercion to participate in any way was exercised, privacy, anonymity and confidentiality was adhered to while debriefing was done with participants that either requested it or the researcher noticed a need for debriefing (Corey et al.,2011;Strydom, 2011:115-122).



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## Appendices

### Questionnaires

#### Section A: Biographical Data

##### 1.1. Gender

Male	
Female	

##### 1.2. Age Group

18-25	
26-35	
Other	

##### 1.3. Marital status

Single	
Married	
Widow	
Divorced	

##### 1.4. Ethnic Group

African	
Indian	
Coloured	
White	
Other	

##### 1.5. Home Language

English	
IsiZulu	

IsiXhosa	
SiSwati	
Other	

## Section B: Problems experienced by community caregivers

2.1. What has been your experience as a community caregiver of people with HIV/AIDS?

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2.2. What work related problems have affected you while discharging your duties?

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2.3. Please indicate the challenges which affect you the most in your work.

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2.4. What has been done to solve these challenges?

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2.5. How could these challenges be solved?

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## **Section C: Perceived effects of community caregiving work**

3.1. How do you feel about your current community caregiving work?

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3.2. How does your work fit into your personal life?

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3.3. What effect has your work had in your family life?

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3.4. What effect has your work had in your relationship with your patients?

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## **Section D: relationship between community caregivers and HIV/AIDS patients**

4.1. How is your relationship between you and your patients? Why do you say so?

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4.2. How is your relationship between you and your family members of your patients? How does this affect your work?

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4.3. What do you think can be done to improve your relationship between you and your patients?

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## **Section E: perceptions on home-base care programme**

5.1. What is your opinion about home-base care programme?

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5.2. What can be done to improve this programme?

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**Umsebenzi ohlobene nezimo eziphathelene nabanikezeli bonakekelo  
kwabane-HIV/AIDS emphakathini waselokishini laseMondlo**

**Ukuhleleka kohlu lwemibuzo**

**Isigaba A: Imininingwane ngomuntu**

**1.1 Ubulili**

Ngingowesilisa	
Ngingowesifazane	

**1.2 Iminyaka yobudala**

Phakathi kweyi-18 – 25	
Phakathi kwengama-26 – 35	
Eminye iminyaka	

**1.3 Isimo somshado**

Angishadile	
Ngishadile	
Ngashonelwa	
Ngehlukanisile umshado	

**1.4 Uhlanga**

Ngingowomdabu wase-Afrika	
Ngingowomdabu waseNdiya	
Ngiyikhaladi	
Ngingowebala elimhlophe	
Olunye	

**1.5 Ulimi lwasekhaya**

IsiNgisi	
IsiZulu	
IsiXhosa	
SiSwati	
Olunye	

## **Isigaba B: Izingqinamba abanikezeli ngonakekelo abahlangabezana nazo**

2.1 Yini osuke wahlangabezana nakho njengomnikezeli wonakekelo kubantu abane-HIV / AIDS?

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2.2 Yiziphi izingqinamba ezihlobene nomsebenzi wakho ezike zakuphazamisa ngesikhathi wenza umsebenzi wakho?

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2.3 Nikeza izinselelo okuyizona zikuphazamisa ngokwedlulele emsebenzini wakho.

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2.4 Yini esike yenziwa ukuxazulula lezi zingqinamba/lezi zinkinga?

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2.5 Zingaxazululwa kanjani lezi zingqinamba/lezi zinkinga?

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**Isigaba C: Imiphumela oyiqaphelayo emsebenzini wokunakekele umphakathi**

3.1 Uzizwa kanjani ngomsebenzi owenza njengamanje wokunakekela umphakathi?

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3.2 Ingabe umsebenzi wakho ahambisana kangakanani nempilo yakho?

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3.3 Ingabe umsebenzi wakho unamphumela muni emndenini wakho?

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3.4 Ingabe umsebenzi wakho ube namiphumela mini ebudlelwaneni bakho neziguli?

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**Isigaba D: Ubudlelwane phakathi kwabanakekeli bomphakathi ne-HIV/AIDS**

4.1 Bunjani ubudlelwane phakathi kwakho neziguli zakho? Kungani usho njalo?

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4.2 Bunjani ubudlelwane phakathi kwakho nemindeni yeziguli zakho? Kukukhubaza kangakanani ukuzimisela emsebenzini kwakho?

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4.3 Yini ocabanga ukuthi ingenziwa ukwenza ngcono isimo sobudlelwane phakathi kwakho neziguli zakho?

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## **Isigaba E: Imibono ngohlelo lokunakekela lwasemakhaya**

5.1 Uthini umbono wakho ngohlelo lokunakekela lwasemakhaya?

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5.2 Yini ocabanga ukuthi ingenziwa ukwenza ngcono lolu hlelo?

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## Permission to conduct the study



health

Department:  
Health  
PROVINCE OF KWAZULU-NATAL

**VRYHEID DISTRICT HOSPITAL**  
Private Bag x 9371, Vryheid, 3100  
Coswold Brown, Vryheid, 3100  
Tel.: 034 982 2111, Fax: 034 9800277  
E-Mail: [Nkosinathi.ndamane@kznhealth.gov.za](mailto:Nkosinathi.ndamane@kznhealth.gov.za)

Enquiries : AN Ndamane  
Date : 05.08.2014

Ms PB Kubheka  
Mondlo Block B 1431  
3105

### **RE: PERMISSION TO MEET COMMUNITY CARE GIVERS-CONDUCTING RESEARCH**

1. Your request dated 31 July 2014 refers.
2. Permission is hereby granted as requested provided that the information :-
  - a. Is used solely for academic and research purposes.
  - b. Is kept in strict confidentiality.
3. Thank you for your co-operation.

  
CHIEF EXECUTIVE OFFICER,  
VRYHEID DISTRICT HOSPITAL

05/08/2014

*Umnango Wezempilo*

*Departement van Gesondheid*  
**FIGHTING DISEASE, FIGHTING POVERTY, GIVING HOPE**

## **ANNEXURE A: PARTICIPANT INFORMED CONSENT DECLARATION**

### **INFORMED CONSENT DECLARATION (Participant)**

Project Title: **Work related conditions affecting community caregivers on HIV/AIDS  
Positive people at eMondlo Township.**

**Phindile Bonakele Kubeka** from the Department of Social work, University of Zululand has requested my permission to participate in the above-mentioned research project.

The nature and the purpose of the research project and of this informed consent declaration have been explained to me in a language that I understand.

I am aware that:

1. The purpose of the research project is to **determine the work related conditions that affect community caregivers of people with HIV/AIDS at eMondlo.**
2. The University of Zululand has given ethical clearance to this research project and I have seen/ may request to see the clearance certificate.
3. By participating in this research project I will be contributing towards **improving our working conditions because research report will be submitted to the organization concerned.**
4. I will participate in the project by **sharing working related conditions of community caregivers and views about HIV/AIDS positive people at eMondlo Township.**
5. My participation is entirely voluntary and should I at any stage wish to withdraw from participating further, I may do so without any negative consequences.
6. I will not be compensated for participating in the research, but my out-of-pocket expenses will be reimbursed. (***Should there be compensation, provide details***)
7. There may be risks associated with my participation in the project. I am aware that
  - a. the following risks are associated with my participation: **I don't anticipate any risk for now.**
  - b. the following steps have been taken to prevent the risks: **Should any emerge, I will strive to minimize or correct them.**
  - c. there is a **0%** chance of the risk materializing.

8. The researcher intends publishing the research results in the form of **sharing findings with the organization concerned, presents papers at conferences and publish academic articles and publish through compilation of dissertation**. However, confidentiality and anonymity of records will be maintained and that my name and identity will not be revealed to anyone who has not been involved in the conduct of the research.
9. I will receive feedback in the form of **research report** regarding the results obtained during the study.
10. Any further questions that I might have concerning the research or my participation will be answered by : **Name : Phindile Bonakele Kubeka**  
**Contact No.: 076 310 8083/ 072 960 0403**
11. By signing this informed consent declaration I am not waiving any legal claims, rights or remedies.
12. A copy of this informed consent declaration will be given to me, and the original will be kept on record.

I, .....have read the above information / confirm that the above information has been explained to me in a language that I understand and I am aware of this document's contents. I have asked all questions that I wished to ask and these have been answered to my satisfaction. I fully understand what is expected of me during the research.

I have not been pressurised in any way and I voluntarily agree to participate in the above-mentioned project.

.....  
**Participant's signature**

.....  
**Date**

## Ethical Clearance Certificate

**UNIVERSITY RESEARCH ETHICS  
COMMITTEE**  
(Reg No: UZREC-171110-030-RA Level 01)



**UNIVERSITY OF ZULULAND**  
Website: <http://www.unizulu.ac.za>

Private Bag X1001  
KwaDlangezwa 3886

Tel: 035 902 6887  
Fax: 035 902 6222  
Email: [ManqeleS@unizulu.ac.za](mailto:ManqeleS@unizulu.ac.za)

### ETHICAL CLEARANCE CERTIFICATE

Certificate Number	UZREC-171110-030-RA Level 01 PGM 2014/95									
Project Title	Work related conditions affecting community caregivers on HIV/AIDS positive people at eMondlo Township									
Principal Researcher/ Investigator	PB Kubeka									
Supervisor and Co- supervisor	Mrs L Shongwe					Prof NH Ntombela				
Department	Social Work									
Nature of Project	Honours/4 <sup>th</sup> Year			Master's		x	Doctoral			Departmental

The University of Zululand's Research Ethics Committee (UZREC) hereby gives ethical approval in respect of the undertakings contained in the above-mentioned project proposal and the documents listed on page 2 of this Certificate. Special conditions, if any, are also listed on page 2.

The Researcher may therefore commence with the research as from the date of this Certificate, using the reference number indicated above, but may not conduct any data collection using research instruments that are yet to be approved.

Please note that the UZREC must be informed immediately of

- Any material change in the conditions or undertakings mentioned in the documents that were presented to the UZREC
- Any material breaches of ethical undertakings or events that impact upon the ethical conduct of the research

The Principal Researcher must report to the UZREC in the prescribed format, where applicable, annually and at the end of the project, in respect of ethical compliance.

The table below indicates which documents the UZREC considered in granting this Certificate and which documents, if any, still require ethical clearance. (Please note that this is not a closed list and should new instruments be developed, these may also require approval.)

Documents	Considered	To be submitted	Not required
Faculty Research Ethics Committee recommendation	X		
Animal Research Ethics Committee recommendation			X
Health Research Ethics Committee recommendation			X
Ethical clearance application form	X		
Project registration proposal	X		
Informed consent from participants	X		
Informed consent from parent/guardian			X
Permission for access to sites/information/participants	X		
Permission to use documents/copyright clearance			X
Data collection/survey instrument/questionnaire	X		
Data collection instrument in appropriate language		Only if necessary	
Other data collection instruments		Only if used	

**Special conditions:** Documents marked "To be submitted" must be presented for ethical clearance before any data collection can commence.

The UZREC retains the right to:

- Withdraw or amend this Certificate if
  - Any unethical principles or practices are revealed or suspected
  - Relevant information has been withheld or misrepresented
  - Regulatory changes of whatsoever nature so require
  - The conditions contained in this Certificate have not been adhered to
- Request access to any information or data at any time during the course or after completion of the project

The UZREC wishes the researcher well in conducting the research.



**Professor Rob Midgley**  
Deputy Vice-Chancellor, Research and Innovation  
Chairperson: University Research Ethics Committee  
28 May 2014

**CHAIRPERSON**  
UNIVERSITY OF ZULULAND RESEARCH  
ETHICS COMMITTEE (UZREC)  
REG NO: UZREC 171110-30

28 -05- 2014

**RESEARCH & INNOVATION OFFICE**



Proof-reading Certificate

PO Box 77214  
Empangeni  
3880

Mobile: 074 9211 480  
Email: zanibaz@yahoo.com



To whom it may concern

This serves to confirm that the document entitled “**Work related conditions affecting community caregivers on HIV/AIDS positive people at eMondlo Township**” has been expertly proofread and edited.

Date: 2015/07/06



X

Dr Berrington Ntombela  
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Research topic: Work Related Conditions Affecting Community  
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Name : Phindile Kubeke Student No: 200701106 Research topic: Work Related Conditions Affecting Community Care Givers on HIV/AIDS Positive People at eMondlo Township CHAPTER ONE 1. ORIENTATION OF THE STUDY 1.1 Introduction The researcher in this work conducted a study assessing work related conditions that affect community caregivers of HIV/AIDS positive people at eMondlo Township. The emphasis of this study was on establishment of work supporting systems necessary to improve work conditions of community caregivers. The effect of HIV/AIDS in South Africa especially in KwaZulu-Natal has contributed to a large number of people who are infected and affected by this pandemic. This has led to healthcare facilities getting overwhelmed by the large number of HIV/AIDS patients who require health

**ANNEXURE A: CANDIDATE'S ORIGINALITY DECLARATION (RESEARCH PAPERS, MINI-DISSERTATIONS, DISSERTATIONS AND THESES)**

**ORIGINALITY DECLARATION**

<b>Full Names and Surname</b>	KUBEKA PHINDILE BONAKELE
<b>Student Number</b>	200731106
<b>Title of dissertation/thesis</b>	WORK RELATED CONDITIONS AFFECTING COMMUNITY CAREGIVERS ON HIV/AIDS POSITIVE PEOPLE AT eMONDLO TOWNSHIP.

I acknowledge that I have read and understood the University's policies and rules applicable to postgraduate research, and I certify that I have, to the best of my knowledge and belief, complied with their requirements.

In particular, I confirm that I had obtained an ethical clearance certificate for my research (Certificate Number **UZREC-171110-030-RA**) and that I have complied with the conditions set out in that certificate.

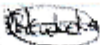
I further certify that this research paper/ mini-dissertation/ dissertation/ thesis is original, and that the material has not been published elsewhere, or submitted, either in whole or in part, for a degree at this or any other university, except as follows:

.....

*(Where part of the work has been published elsewhere, or where the work is a continuation or progression of research that was submitted for another degree, e.g. an Honours project or a Master's dissertation this must be stated clearly, the name of the work must be provided, and an explanation must be given regarding the extent of the current work's originality.)*

I declare that this research paper/mini-dissertation/dissertation/ thesis (~~delete that which is not applicable~~) is, save for the supervisory guidance received, the product of my own work and effort. I have, to the best of my knowledge and belief, complied with the University's Plagiarism Policy and acknowledged all sources of information in line with normal academic conventions.

I have/have not subjected the document to the University's text-matching and/or similarity-checking procedures. *(One could indicate that this process applied only to some chapters or that it occurred during the course of the research and not in respect of the final product.)*

<b>Candidate's signature</b>	
<b>Date</b>	19-11-2015

**ANNEXURE C: CANDIDATE'S NOTICE OF INTENTION TO SUBMIT A DISSERTATION OR THESIS FOR EXAMINATION**

The Head of Department  
Department of Social work  
Faculty of Arts  
University of Zululand

**NOTICE OF INTENTION TO SUBMIT A MANUSCRIPT FOR EXAMINATION**

I hereby give notice that I aim to submit my dissertation/ thesis for examination. I undertake to inform the University immediately in the event of a delay in submitting the manuscript by the date stipulated above.

Full Names and Surname	PHINDILE BONAKELE KUBEKA
Student Number	200701106
Intended date of submission	19-11-2015
Degree	MASTER'S IN SOCIAL WORK
Name of Supervisor	PROF. N.H NTOMBELA
Supervisor e-mail address	NtombelaN@unizulu.ac.za
Name of Co-supervisor	MRS C.H.N SHONGWE
Co-supervisor e-mail address	Lungi.shongwe@gmail.com
Title of dissertation/thesis	WORK RELATED CONDITIONS AFFECTING COMMUNITY CAREGIVERS ON HIV/AIDS POSITIVE PEOPLE AT eMONCLO TOWNSHIP
Candidate's signature	
Date	19-11-2015

