

https://dspace.org/

Perceptions of health and well-being among caregivers of people living with HIV/AIDS.

Shobede, Sindile L.

2011-06-21
http://hdl.handle.net/10539/10141

Downloaded from a DSpace repository. https://dspace.org/

PERCEPTIONS OF HEALTH AND WELL-BEING AMONG CAREGIVERS OF PEOPLE LIVING WITH HIV/AIDS

A research report submitted in partial fulfillment of the Degree Master of Arts (Clinical Psychology) by coursework in Psychology, School of Human and Community Development, at the University of Witwatersrand, Johannesburg, South Africa.

Submitted by: **Sindile L. Shobede**

Supervised by: **Dr. M. Kasese-Hara**

May 2011

Declaration

I declare that this research report is my own unaided work. It is submitted in partial fulfillment of the requirements for the Degree of Masters of Arts (Clinical Psychology) in the Department of Psychology, School of Human and Community Development, University of the Witwatersrand, Johannesburg, South Africa. It has not been submitted before for any other degree or examination at any other university or institution.

Signature _____ Date _____

Copyright Notice

The copyright of this thesis rests in the University of the Witwatersrand, Johannesburg, South Africa, in accordance with the University's intellectual Property Policy.

No portion of the text may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, including analogue and digital media, without permission from the University. Extracts of or quotations from this thesis may, however, be made in terms of Sections 12 and 13 of the South African Copyright Act No. 98 of 1978 (as amended), for non-commercial or educational purposes. Full acknowledgement must be made to the author and the University.

An electronic version of this thesis is available on the Library webpage (www.wits.ac.za/library) under "Research Resources". For permission requests, please contact the University Legal Office or the University Research Office (www.wits.ac.za).

Acknowledgements

Mom, before I thank you, I'd like to give God the honour for giving me a mother like you. I thank you for giving me an opportunity to get an education. I am forever grateful to you for your unconditional love and support. You stood by me all the way and you stood firm even when I did not deserve it. Like your name Stella Khethiwe Shobede, indeed you were chosen to be a star and that gleam of light in the dark and in stormy weather. Without you, this would not have been possible, you are the best! To my son Sibonelo, thank you for understanding-as young as you are-that I could not give you the full attention that you deserved because I had to study. To my late grandmother MaMokoena, thank you for stepping in when I needed you the most, may your soul rest in peace. My Uncle, Lazarus, thank you for being granny's right hand man in looking after my son. Tintswalo, my dear sister, thank you for being a mother to my son during my studies. To all my relatives, especially Kedibone Nkhoma and Gladness Shobede-Mushwana thank you for showing interest in my success. To all my friends, thank you so much for your presence in my life; without your continuous support and encouragement I wouldn't be where I am now.

A special thank you to my former supervisor Ms. Hesty Enrody-Younga for leaving me in the capable hands of my current supervisor, Dr. Mambwe Kasese-Hara. Mambwe, thank you so much for taking time to supervise me. Thank you for believing in me and being patient with me. You were more than a supervisor; you were a friend, a counselor and my spiritual sister. I thank God for making our paths cross, it was for a purpose beyond the call of duty and I thank you for responding to it. To Prof. Carol Long and Prof. Gill Eagles thank you for believing in me and encouraging me to go on when I had lost all hope. To the 2007 MA CLIN team and class, thank you for all your support and input and making this journey worthwhile-you are always in my thoughts. To my former Colleagues Dale Moodley and Bongiwe Mahlobo thank you for your support.

I would like to thank Mavis Mahlangu the project manager at Bophelong/Empilweni community project for a very warm welcome and for permitting me to use their facility and caregivers for my research. To the project managers at Helping Hands Home-Based Care, thank you for your warm welcome and permission to use caregivers from your project for my research. To all the caregivers that took part in this research, if it were possible I would write down all your names and thank you individually. I thank you from the depths of my heart for taking time to participate in this study, without you there would be nothing to say. You are the heart of this project and may God bless all of you.

To those I did not mention-you are not forgotten, thank you for having faith in me your, support means a great deal.

Abstract

The current study aimed at exploring the effects of caring on the health and well-being of caregivers caring for people living with HIV and AIDS. Another aim of the study was to investigate the availability, use and effectiveness of support for the caregivers. The sample comprised of seven Home-Based Care caregivers that volunteered to participate in the study. Participants were sourced from two community organizations located in Tembisa. Data was gathered through individual semi-structured interviews and analyzed through thematic content analysis.

Results indicated that the caregivers were affected both positively and negatively by their work on various levels-including physical, emotional and spiritual spheres. The results in the current study also showed that the participants used more than one form of support including themselves, colleagues, friends and family. Thus in the response to the secondary aim of this study; results indicate that the caregivers have little external support. The results also showed that project managers and social workers were often used for technical support only. The participants mostly used faith based activities such as prayer, reading the bible and going to church or listening to gospel music as strategies for coping. Other forms of coping employed by some of the participants included watching television, listening to the radio, sleeping and doing house chores.

TABLE OF CONTENTS

Declaration……..2
Copyright notice…….....3
Acknowledgements…….....4
Abstract……...5

Chapter 1: Introduction……....9

1.1 Introduction of the study……...9
1.2 Aims…….10
1.3 Rationale……..…10
1.4 Research Questions……..11
1.5 Background and Context……..12
1.5.1 Bophelong/Empilweni Community project……...12
1.5.2 Helping Hands Home-Based Care…….13

Chapter 2: Literature Review.....14

2.1 Defining and identifying caregivers…….14
2.2 Motivation to care and the benefits of caring……..15
2.3 The burden of care……...17
2.4 Stigma and discrimination in caring……22
2.5 Support for caregivers……..23
2.6 Conclusion……...24

Chapter 3: Research Method…….25

3.1 Research Design……...25
3.2 Sampling……..25
3.3 Data gathering and analysis…….26
3.4 Ethical considerations……..27

Chapter 4: Results and Discussion……28

4.1 Overview of results……..28
4. 2 Demographic information……...28
4.3 Training and preparation…….....30
4.4 Caregivers' health and well-being……...32
4.4.1 Motivation…….33
4.4.2 Benefits…….37
4.4.3 Challenges……40
4.4.3.1 Lack of material……40
4.4.3.2 Fear of infection……40
4.4.3.3 Lack of interest from family members……..41
4.4.3.4 Rejection by patients……42
4.4.3.5 Poor funding……..42
4.4.3.6 Heavy workload…….43
4.4.3.7 Loss due to death……...43
4.4.3.8 Work related problems……..43
4.4.4 Aspects of caring……..45
4.4.4.1 Physical aspect…….45
4.4.4.2 Emotional aspect……..46
4.4.4.3 Spiritual effects……48
4.4.5 Coping strategies…….....49
4.5 Discussion……51

Chapter 5: Conclusion.....53

5.1 Summary of study……53
5.2 Limitations of the study……...54
5.3 Recommendations……54
5.3.1 Recommendations for caregivers and the organizations……..54
5.3.2 Recommendations for future research...……...55

Appendices……56

Appendix A: Interview schedule……...56
Appendix B: Letter of request……57
Appendix C: Participant information sheet……58
Appendix D: Participant consent form……..59
Appendix E: Interview and recording consent form…….60
Appendix F: Letter of permission (Bophelong)……61
Appendix G: Letter of permission (Helping Hands)……..62
Appendix H: Ethics clearance certificate...……....63

Reference List……...64

List of tables

Table 1: Caregivers' personal information……28
Table 2: Summary of type and duration of training……...31
Table 3: Motivation themes……...33
Table 4: Benefit themes…….38
Table 5: Summary of themes of challenges faced by caregivers……...44
Table 6: Coping strategy themes……49

List of figures

Figure 1: Types of training institutions……..30
Figure 2: Reported benefits……38
Figure 3: Summary of challenges……..44
Figure 4: Effects of caring……49

CHAPTER 1: INTRODUCTION

1.1 Introduction

The effects of HIV and AIDS have been researched and studied in various spheres including medical, economical, industrial, social, political and familial impacts of the pandemic. Reports by the World Health Organization (WHO) and UNAIDS in 2006 indicated that off the 39.5 million people in the world living with HIV, 64% of those, lived in sub-Saharan Africa (cited in department of health, 2007). The South African department of health further cited reports that estimated that 5.54 million people were living with HIV in South Africa alone in 2005 (department of health, 2007). Although the South African department of health reported a decline towards stabilization in the prevalence of HIV, they maintained that HIV and AIDS are still the main challenge in South Africa (department of health, 2007).

The escalation of death due to HIV and AIDS related disease has led to the development of a network of home care for the terminally ill, in order to reduce the burden of care on the health system (Marais, 2005). As a result hospitals are discouraged from admitting AIDS patients in order to ensure that '*AIDS patients do not take beds away from other patients*' and to ensure that patients get the chance to spend their last days with family whilst receiving care from trained carers (Barolsky, 2003, p24). These kinds of networks were part of the "*bid by the health care system to ensure that 'care in the community' became 'care by the community*'" (Marais, 2005, p65). For AIDS patients to be cared for at their homes by trained carers it implies that someone has to be responsible for that task. In the South African context, because of limited public resources, community organizations and non-governmental organizations as well as households all stepped in to bridge the gap (Marais, 2005). With a total of 466 home/community based care programs in place, and 9553 volunteers and 370 172 people accessing them (cited in Barolsky, 2003); it is evident that there is a great disproportion of caregivers to patients, with an estimated caregiver ratio of 1:32 recipients and each program catering for approximately 659 recipients. Given such statistics, it is disappointing to learn that there are still limited studies looking at the effects of care-giving on caregivers of people living with

HIV/AIDS, which led to the launching of this study, the aims of which are discussed below.

1.2 Aim

The aim of this study was to explore both positive and negative effects of caring on the health and well-being of home-based care project caregivers. The secondary aims of the study were to evaluate the type, availability, use and effectiveness of support services for caregivers of people living with HIV/AIDS in a home-based care project.

1.3 Rationale

According to the department of health (2007), there has been a rapid growth of community and home-based care programs. However, literature still indicates that little investigation work exists in South Africa on the psychosocial impacts (Orner, 2006) and the well-being of caregivers of people living with HIV (Webb-Robinson & Wilson, 2008). Although there is a rise in international studies on the role of caregivers of people living with HIV/AIDS few studies have examined the factors associated with depression in the caregivers (Pirraglia et al, 2004) a commonly cited feature in reports of effects of caring. Most research continues to focus mainly on the patient (Webb-Robins & Wilson, 2008) and thus neglecting the people that care for the patients. Studies that tend to look at the impacts of HIV/AIDS are mostly economical and focus on rural households and communities (Barnett & Whiteside, 2002 & Marais, 2005) neglecting urban areas, and more worryingly, peri-urban areas and slums (Whiteside & Sunter, 2000). It was on these premises that the current study was conducted to look into the effects of care giving on the health and well-being of caregivers in a peri-urban setting.

The current study also purports to add some balance in the current skew in researches of HIV/AIDS impact on caregivers. D'Cruz (2004) highlighted that most caregiver studies

focus on the negative effects of caring and thus called for studies that will investigate both negative and positive consequences of caring on the caregiver, as well as studying the role of care in various contexts. This call of viewing both positive and negative impacts of caring is in line with the literature that indicates that despite the challenges facing caregivers of people living with HIV; some caregivers report feeling a sense of pride in their roles (Webb-Robins & Wilson, 2008), which is a positive attribute to caring. Similarly, Pakenham and McClausand (2003) had also advocated for more research into the positive and negative experiences of caring on caregivers after finding that nearly half of the respondents in their study had reported personal growth as a benefit from their care-giving experience. The current study was a response to this call in an attempt to expand on the few studies that exist.

In addition, most existing international studies have been conducted on informal caregivers in homosexual communities and especially in gay and bisexual men (Pirraglia et al 2004) as well as informal carers in the household for example, Orner (2006). Because of the nature of home-based care projects- caregivers being volunteers in certain organization or community structures-there seems to be a salient unspoken assumption that they are well supported by their organizations and are not affected as much because they are not have close relations with the AIDS patients. So this study also looks into the motivation of care from the caregivers' perspective, as some are motivated by the closeness of the disease-such as being infected themselves or having a close relative living with HIV or knowing someone that had died of AIDS.

1.4 Research Questions

The current study intended to answer the following questions:

- What motivates and sustains care-giving among caregivers of people living with HIV/AIDS?

- What are the effects (benefits and burdens) of care-giving on the health and well-being of the caregiver? i.e. how caring affects caregivers' physical, emotional or spiritual being?
- How do caregivers experience their role and how prepared do they feel in terms of their skills training?
- Do caregivers use support services, and if so, how do they experience them in terms of availability, accessibility and effectiveness?

1.5 Background and Context

1.5.1 Bophelong/Empilweni Community Project

Bophelong/Empilweni Community Project was established in 1999 by the late Cithi Fakude together with Dudu Masemola, in Tembisa at Ekurhuleni (East Rand). The project was apparently registered with the department of social development in the year 2000 as the only project providing home-based care for people living with HIV and those suffering from AIDS in Tembisa. The founders apparently requested help from a retired nurse for skills training and later did the "69 Days"-a training course that provides caregivers with basic caring skills which runs for 69 days conducted by the department of health. They then started hospital and home visits to establish relationships with the patients and their families.

The project is currently run in the Baptist Convention Church with thirty-one staff members. There are reportedly twenty caregivers in the project which are equally divided into two, namely, the Home-Based Care (HBC) caregivers and OVC (Orphans and Vulnerable Children) caregivers. They each have a single coordinator and administrator. There are apparently three auxiliary social workers, a nurse, poverty alleviation coordinator, a cook as well as the project manager. The project runs a support group for people living with HIV and a day care center for children up to the age of six years. The responsibility of caregivers in the project includes tracing antiretroviral treatment

defaulters, DOT (Direct Observation Treatment) for patients with Tuberculosis, psychosocial and HIV counseling as well as providing practical care for terminally ill patients. Each caregiver apparently cares for approximately ten patients a day. The caregivers used to have group debriefing sessions once a month with the help of Love Life, but that ceased in 2006. Since then, they sit in a group and discuss their cases but without a professional counselor; however, they were promised a professional counselor from Australia by the Baptist Convention Church.

1.5.2 Helping-Hands Home-Based Care

Helping Hands Home-Based Care was established in June 2001 and is registered as a Non-Profit Organization. It is currently managed by Ms. Doris Vilakazi with the help of Ms. Albina Maleka, a professional nurse. The project operates under a rented room at Esangweni crèche in Tembisa.

The staff seemingly consists of the above-mentioned leaders, an administrator and sixteen community health workers. The health workers comprise of ten Home-Based carers and six child minders caring for orphans and vulnerable children. The project is involved in three main activities, namely, Home-Based Care (HBC), Orphans and Vulnerable Children (OVC) and food gardens. The food garden had to be temporarily stopped due to lack of space.

The HBC caregivers tasks include caring for bed-ridden patients through home visits, providing psychosocial support and education to HIV/AIDS clients through door-to-door campaigns, and providing Direct Observed Treatment (DOT) support to clients with Tuberculosis (TB) as well as HIV positive clients already on Antiretroviral treatment.

CHAPTER 2: LITERATURE REVIEW

2.1 Defining and identifying caregivers

To define and identify caregivers, one has to understand what caring or care-giving means. Most writings about caregivers and care-giving seem to assume that there is a common understanding of what caring means. However, according to Montgomery (1993) and Held (2006) that is not the case among writers of care as there is no consensus about the meaning of care. Held (2006) also noticed that there is a tendency among writers of care to shy away from defining caring, which she also did; however she described caring as the meeting of objective needs of another who cannot. She also stated that caring is partly an "*attitude, motive and value*" (p30). Montgomery (1993) after noting that caring was not well represented in theoretical literature and that it was widely trivialized; she described caring as "*a way of being, a state of responding to others…and requires personal involvement, it is the antithesis of alienation, detachment or apathy…a natural condition of being human*" (Montgomery, 1993, p13). In short, the two writers indicate that caring is a relationship between two people-the one that provides care and the one that needs or receives care. Thus a caregiver can be defined as a person that is motivated by various reasons to be personally involved in meeting the objective needs of others that cannot.

Caregivers mainly comprise of volunteers, both formal and informal (UNAIDS, 2000). Informal volunteers are often family members, friends, neighbours or members of a church (UNAIDS, 2000). Formal volunteers are those that are recruited, trained and supervised by the organizations they are contracted to (UNAIDS, 2000). However, in the South African context volunteers *"tend to emerge haphazardly, separately struggling along similar learning curves"* (Marais, 2005, p68). Generally, caregivers are trained to recognize health problems and treat them or refer when necessary; help with domestic chores; liaise with health and welfare services on behalf of the person living with HIV or AIDS; provide emotional support and counseling for people living with HIV or AIDS

and their families (UNAIDS, 2000; Wight, LeBlanc & Aneshensel, 1998) and to disseminate information (Abrahamsohn, 1994).

In many contexts the responsibility of caring is mostly borne by women (UNAIDS, 2000; Mango, 2004; Marais, 2005; Orner, 2006; Opiyo, Yamano & Jayne, 2008; UNAIDS, 2008; Webb-Robins & Wilson, 2008 Kangethe, 2009). As Marais (2005) puts it: "*Home- and community-based care are melded into the largely invisible and taken-for-granted labour women perform in the care economy*" (p67). Although the trend seems to be changing, with some men doing care work (UNAIDS, 2000); the ratio is still significantly low (UNAIDS 2008). There seems to be no consensus when it comes to the approximate age of the caregivers; as some reports highlight that most caregivers are young women in their childbearing years (Webb-Robinson & Wilson, 2008) whilst others (Kangethe, 2009 & UNAIDS; 2008) reported that the majority of caring lies on older women. The reason for this may be because most existing studies have mainly focused their attention on elder caregivers such as grandparents of AIDS orphans and parents of HIV infected persons and those of AIDS patients. What is apparent however, is that irrespective of age-they may be young, they may be old or somewhere in between-caregivers are most likely to be female (Barolsky, 2003).

2.2 Motivation to care and the Benefits of caring

Volunteers are motivated by various reasons, including compassion, self interest, a sense of religious duty, the need to control the disease, and the hope for a paid income and incentives offered by volunteer programs (UNAIDS, 2000). Brems (2001) also identified eight reasons why people choose to enter the helping profession and they included:

i. The desire to help;
ii. The desire to change the world;
iii. The desire to create purpose and meaning;
iv. The desire for self help;

v. The desire to control or tell others what to do;
vi. The desire to share experience of recovery;
vii. The desire to share personal insights or wisdom and
viii. The desire for financial freedom and status.

However, many caregivers in HIV/AIDS care are motivated by the fact that they themselves are also living with the virus (Wight, LeBlanc & Aneshensel, 1998; UNAIDS, 2000; UNAIDS, 2008). Further evidence of this fact is found in the study by Pirraglia et al (2004) on the relationship between depression and caregiver burden among informal caregivers of people living with HIV or AIDS. The study revealed that nearly half of the caregivers in the 176 patient-caregiver dyad were HIV positive. It is apparent that caregivers are motivated by many reasons which may probably influence what caregivers consider as benefits from their work.

D'Cruz (2004) highlighted that most caregiver studies focus on the negative effects of caring; she called for studies on the view that covers both negative and positive consequences of the role of caring on the caregiver. Pakenham and McClausand (2003) had also identified that few studies examined variations in caregiver adjustment and those that did, had some weaknesses. They then embarked on a study to explore the benefits associated with HIV/AIDS care-giving and to examine relations between *caregiver adjustment and benefit finding and stress and coping variables'* (p857). Benefit finding '*refers to the belief that an event has revealed or evoked positive personal qualities, such as an increased understanding of others, or has enhanced an appreciation for life and existing relationships'* (p854). Taylor (1983) and Taylor and Armor (1996) cited in Pakenham and McClausand (2003) suggest that maintaining self-esteem depends on benefit finding. This study, conducted in Australia, recruited participants from gay and lesbian communities. A total of sixty-four (thirty-eight males and twenty-six females) caregivers were involved in this study. Data was gathered using semi-structured interviews; an interview schedule was used to obtain information on biographies, care-giving context and global health. Due to an administrative error, fifty-eight caregivers were asked the benefit finding question and 97% of them reported benefits. Only two of

the fifty-eight reported no benefit at all. Using content analysis, the following eight themes emerged from the interviews:

1. Personal growth (41% reports)
2. Increase in understanding of others (24% reports)
3. Positive personality change (22% reports)
4. Increase in knowledge of HIV/AIDS (19% reports)
5. Start of a new relationship (17% reports)
6. Strengthening of existing relationship with care recipient (16% reports)
7. Sense of satisfaction and achievement (16% reports)
8. Gained perspective (12% reports)

Results showed that benefit finding was negatively associated with depression and positively associated with social support use, seeking social support coping and problem-solving coping. What this study suggests is that caregivers that find benefit in their work are likely to not be negatively affected by their work. Some local studies have also made indirect nuances towards these findings. For instance Mathebula (2006) found that 70% of the participants in the study reported that they enjoyed providing care because they were doing it out of compassion. Similarly, Sibuye (2008) found that the caregivers in the study were motivated by making a difference to the life of the group that society discriminated and regarded their role as a calling from God. The above findings indicate that caring has benefits for the caregiver, however as earlier indicated that such aspects have not been widely researched. Moreover, studies that have looked at the effects of caring, have focused on the negative ones. It is therefore necessary to investigate the effects of caring holistically looking at both negative and positive effects on the carer.

2.3 The burden of care

One of the first international reports on caregivers of people living with HIV/AIDS by the UNAIDS (2000) stated that caregivers usually experience stress and burnout. Burnout is described as "*not an 'event' but a process in which everyday stresses and anxieties that*

are not addressed gradually undermine the carer's mental and physical health, so that eventually care-giving and personal relationships suffer" (UNAIDS, 2000, p25). The South African Department of health describes burnout as "*a state of physical, emotional and mental exhaustion*" (Department of Health, 2008, p39-4). Apart from burnout, caregivers and counselors suffer from compassion fatigue, which is "*a state of tension resulting from repeated preoccupation with patients' trauma, manifesting in re-experience of the trauma, avoidance or numbing of reminders of the trauma and persistent arousal*" (Department of Health, 2008, p39-4). Both burnout and compassion fatigue compromise the well-being of a caregiver (Department of Health, 2008). According to Pakenham, Dadds, & Terry (1998) and the UNAIDS (2000) stress affects physical and mental functioning as well as personal and/or social functioning. As shown above, the task of caring poses risk on many levels of the life of the person providing the care. The various signs and symptoms of the effects of caring are discussed below.

The UNAIDS (2000, p26) listed the following signs of stress:

- Loss of interest in and commitment to work;
- Loss of punctuality and neglect of duties;
- Feelings of inadequacy, helplessness and guilt;
- Loss of self confidence and self esteem;
- A tendency to withdraw-both from clients and from colleagues;
- Loss of sensitivity in dealing with clients;
- Loss of quality in performance of work;
- Irritability;
- Difficulty getting on with people;
- Tearfulness;
- Loss of concentration;
- Sleeplessness;
- Excessive fatigue;
- Depression and
- Bowel disturbance.

This list is not exhaustive other reports include experiences of anxiety, insomnia, fatigue, muscle strain, head and stomach aches (Kespichayawattana & VanLandingham, 2002). According to other findings, medical co-morbidity is common among caregivers (Pakenham, Dadds & Terry, 1998; UNAIDS, 2000; Knodel, Saengtienchai, Im-em & VanLandingham, 2000; Kespichayawattana & VanLandingham, 2002 and Pirraglia et al, 2004).

Kespichayawattana and VanLandingham conducted a survey in 2002 in Thailand exploring health impacts of care-giving on older parents who had a child die of AIDS. Their sample comprised of purposively selected 394 AIDS affected households and a control group of 376 non-affected households. A total of 649 AIDS parents and 621 control parents were interviewed. The results indicated that 43% of the parents that co-resided with their children found the care-giving tasks (ranging from food preparation, transportation, lifting and moving the sick child) most problematic because they were strenuous and time consuming. This is due to the caregivers' involvement in multiple tasks, which leaves them little or no time to attend to their own needs (Wight et al, 1998 & Simpson, 2006). In addition, caregivers often lack the time to care for themselves because not only are they caring for the sick person but in some cases they provide care to other individuals besides the person living with HIV or AIDS (Pirraglia et al, 2004). This greatly compromises the ability to care. According to Brems (2001) self-care is a significant tool to use to avoid burnout and negative impacts in the helping profession. To care for one's self one has to have the time to do that. With little or not time to themselves, carers may end up neglecting their own needs and thus provide poor care to the care recipient. Only 13% of the participants in the study by Kespichayawattana and VanLandingham (2002) reported emotional strain. This was different from an earlier study by Knodel, Saengtienchai, Im-em and VanLandingham (2000) on the impact of AIDS on older persons in Thailand where emotional strain was the most commonly cited burden wherein 42% of all cases reported this. This is consistent with a later study by Pirraglia et al (2004) which investigated the relationship between depression and caregiver burden in the United States of America among informal caregivers of people

living with HIV. Results indicated that care-giving was strongly associated with depression. Although there is variation in the above studies, the core factor in the results is that care-giving has negative effects on the caregiver on the physical and emotional level.

Other findings of care-giving outside the scope of HIV/AIDS, report similar experiences of stress and strain on caregivers. For example, Felemengas (2005) in her study of the effects of stroke on caregivers and their families found that a majority of her participants reported that aspects of care-giving were difficult and had biological, psychological and social ramifications. Some of the themes in this study included '*role changes; relationship disruption; irritability; social constraints; exhaustion; anxiety; depression; occupational implications and financial problems*' (Felemengas, 2005, p62-63) Similarly, caregivers of children with cerebral palsy suffer the burdensome effects which impact on their psychological and physical health (Raina et al, 2004).

In the South African context, the epidemic's impact is complex and varying particularly at household level (Marais, 2005). Much of what is known about the epidemic is based on rural observations and studies (Barnett & Whiteside, 2002 & Marais, 2005) where HIV prevalence is often lower than in urban settings. Whiteside and Sunter (2000) had previously reported that most of HIV and AIDS research had neglected the urban areas, peri-urban areas and slums. Even in later years the problem still seems to exist (Marais, 2005). Marais (2005) also noted that there was a tendency in literature to over-generalize unnecessarily. It also seems as though most research often shies away from the social dynamics that underpin the AIDS epidemic (Barolsky, 2003; Marais, 2005).

Simpson (2006) conducted a study at Care Community Project in Kwa-Zulu Natal province to assess whether caregivers at the project were receiving sufficient psychological support. Results indicated that care-giving affects caregivers' mental, physical and spiritual health. Most of the caregivers experienced signs of burnout manifesting in the form of lack of sleep, feeling tired all the time, loss of confidence and anxiety. These findings were consistent with some of the international findings discussed

above. However, contrary to other findings (Knodel, Saengtienchai, Im-em & VanLandingham, 2000; Kespichayawattana & VanLandingham, 2002) for this sample, financial burden was found to be the main stressor. This could be because of the devastating economic effects of HIV/AIDS (Sunter & Whiteside, 2000). This finding was also cited by Marais (2005) who stated that home- and community-based care does not come cheap because much of the costs of care are reduced for the national health system and displaced onto people living with HIV/AIDS and their caregivers, whereby "*the poor subsidize the poor*" (Marais, 2005, p65).

Levin (2006) conducted a study on guardians caring for children orphaned by AIDS in Vosloorus, Johannesburg. The study revealed that-in the physical sphere-guardians suffered from numerous health problems including sleep disorders, water retention problems, poor eyesight, dental problems, increased blood pressure and related illnesses as well as general malaise. Apart from sleep disorders and general malaise, the health problems cited in this study are not consistent with commonly reported symptoms that result from care-giving. This discrepancy may be due to the fact that the guardians were elderly and their symptoms were because of aging and not as a result of care-giving. This however, highlights the fact given earlier that medical co-morbidity is common among caregivers of people living with HIV. This further emphasizes the fact that many caregivers have a compromised immune system as well. The study also found that many of the guardians were often older people on pension or unemployed and had multiple stressors and traumas, which included loss of children, resuming guardianship under dire financial constraints, bureaucratic difficulties and problems with neighbours (Levin, 2006). The latter part of problems with the neighbours was inconsistent with the findings by Kespichayawattana and VanLandingham (2002). Trauma was also reported by 70% of the participants in Mathebula's study which explored the challenges faced by caregivers at Muslim AIDS Programme (Mathebula, 2006). Trauma seems to stem from issues around death, as seen in Levin (2006), Simpson (2006), Mathebula (2006) and Sibuye (2008). Loss due to death of the patient was reported by Montgomery (1993) as a risk in caring because it often happens suddenly and unexpectedly. Moreover, death frequently occurs when the caregiver and patient have formed a bond. In addition, because caring is

usually an innate response, losing a patient feels like losing a part of you (Montgomery, 1993). This may be the reason why most home-based caregivers experience the death of a patient as traumatic as indicated in the studies by Levin (2006) and Mathebula (2006). Generally, the above studies indicate that the role of caring is not an easy task and that it has many negative consequences.

2.4 Stigma and discrimination in caring

The UNAIDS in 2000, reported that stigma was one of the problems that made care-giving hard. Families tend to respond in dramatic and punitive ways to HIV and AIDS making disclosure difficult; moreover, due to the catastrophic costs of care infected individuals are often rejected and resented (Barolsky; 2003). Even later studies and reviews conducted in South Africa found that stigma was still a challenge that many people living with HIV and their caregivers were facing (Mango, 2004 and Skinner & Mfecane, 2004). Stigma not only affects the infected person, it also affects all those associated with the disease (Skinner & Mfecane, 2004) and tends to increase distress levels (Orner, 2006). It can also impact on society and thus undermining existing interventions as association with a person or people living with HIV may render the associated person vulnerable to exclusion (Skinner & Mfecane, 2004). According to Marais "*stigma legitimizes the decision to withdraw sympathy and assistance. AIDS is transformed from social plight into private misfortune… Stigma has an imprisoning effect, locking caregivers-who have often already reduced their social contact…*" because it affects whether and how people engage with the health care system or home- and community-based care interventions (Marais, 2005, p66). Stigma keeps the cycle of silence and secrecy rolling (Barolsky, 2003; Marais, 2005). This may be the reason why research is lacking in this field-people may still be afraid to disclose information that links them to the epidemic. On the contrary Barolsky (2003) noted that although stigma is still evident in communities there is a reduction to its depth and extent. This implies that the stigmatization of people living with HIV and their caregivers may often go unrecognized because of its subtlety.

2.5 Support for caregivers

Given the response that HIV and AIDS have received since its discovery, it would be expected that psycho-social support and care is sufficiently available for those caring for people living with HIV or AIDS. A study in America by Wight, LeBlanc and Aneshensel (1998) found that there was an overall increase in the use of emotional support services by participants in their sample. Results showed that four out of the ten caregivers used emotional support services. Factors affecting the use of support services by caregivers included caregivers HIV status, educational background and co-residence with the person living with HIV. It emerged from the study that HIV positive caregivers were likely to use support services. Moreover, caregivers with higher education qualifications used support services more often than those with lower education levels. Although there were issues of time constraints reported by the participants, co-residence with the person living with HIV seemed to increase the possibilities of support service use by caregivers (Wight, LeBlanc & Aneshensel, 1998). Caregiver support, especially practical support, was found to be lacking for the caregivers in this study as a majority of them indicated that additional services would be helpful for them (Wight, LeBlanc & Aneshensel, 1998). Although the use of support services is known to reduce depression and anxiety among caregivers, research indicates that most caregivers do not use support services because they do not know how to access support (Family Caregiver Alliance-FCA, 2005).

Mango (2004) evaluated the use of psychological services by individuals living with HIV or AIDS and their communities in Lusikisiki in the Eastern Cape. The researcher gathered information by interviewing both service providers and users and conducted a focus group with community members. The study revealed that there was little psychological support available for family, friends and communities of people living with HIV or AIDS as much intervention focused on the infected person (Mango, 2004). Although service providers faced the challenge of shortages in the form of lack of infrastructure, transport and training as well as limited staff, the study revealed that the services were to some extent accessible, acceptable, and affordable and offered continuously. An almost similar study was conducted by McKenzie (2005) in the North-

West province assessing the psychological support given and received by home-based caregivers. The study showed that the caregivers received adequate and appropriate support within their programs and on the outside as well. They received support in the form of supervision, debriefing, psycho-education as well as emotional and spiritual support. However, the participants in this study highlighted the need for more supervision and debriefing sessions. A later study by Simpson (2006) assessing whether caregivers of people living with HIV/AIDS received sufficient psycho-social support revealed that the caregivers were not receiving sufficient psycho-social support to help them cope. The results showed poor access to and use of emotional support by caregivers. Caregivers felt that they had inadequate skills, training and supervision. They also cited that lack of medication and care materials as well as lack of proper referral mechanisms made them feel less supported in performing their tasks.

It is evident from the above studies that the issue of support for caregivers still needs to be explored further as there is no consensus in the findings. The above results suggest that support for caregivers of people living with HIV/AIDS is contextual and cannot be generalized for all populations. It is also evident that there are many factors affecting the use of support services by caregivers of people living with HIV/AIDS.

2.6 Conclusion

The reviewed literature indicates that indeed most existing studies focus on negative impacts of caring as highlighted by D'Cruz (2004) and supports the call she made for studies that will look at care-giving in a holistic view as also indicated earlier by Pakenham and McClausand (2003). There seems to be an indication that some caregivers enjoy their duties or find benefit from their work; however this variable has not been explored much by most existing studies.

It is also evident that in the Southern African context research still very much neglects studying peri-urban areas and slumps (Marais, 2005). The studies cited in this review

were mainly located in rural areas for example Mango (2004), McKenzie (2005), Simpson (2006) and Kangethe (2009); and those conducted in urban areas were on sites that were fairly well established and developed, for example Mathebula (2006). Moreover, there appears to be varying results in terms support use by caregivers as some studies reveal that more caregivers use support services whilst others report the opposite. Much of the existing caregiver studies are based on informal caregivers in households-such as friends and families of people living with HIV/AIDS-but not on volunteer caregivers within community organizations.

CHAPTER 3: RESEARCH METHOD

3.1 Research Design

The current study followed a qualitative inquiry because it was interested in the perceptions from Home-Based Care caregivers about the effects of their work on their health and well-being. Qualitative research is a naturalistic and holistic inquiry that aims at understanding social life, and reaching time and context specific generalizations based on people's subjective experiences (Sarantakos, 2000).

3.2 Sampling

Participants of the current study were sourced out from two community organizations, namely, Bophelong/Empilweni Community project and Helping Hands Home-Based Care. A brief meeting was arranged and held separately with the caregivers from the two organizations with the help of the project managers (i.e. in terms of the availability of caregivers). At the meeting the caregivers were thoroughly informed about the details of the research and allowed to ask questions, and then they were invited to volunteer in the study. At the end of each meeting the caregivers were handed information sheets (Appendix C) which contained information about the research, and participant consent

forms (Appendix D) where they would indicate if they wish to participate in the study or not. In the first meeting at Bophelong, nine caregivers attended the meeting and seven of them immediately gave consent to participate in the study. Off the seven caregivers that gave consent, two were withdrawn from the study because of time constraints (they could not make time for the interview). One participant also had to be withdrawn because she was involved in the OVC Programme and not the Home-Based Care Programme. This meant that only four caregivers from Bophelong could participate in the study. Caregivers from Helping Hands were also approached in a manner similar to that of Bophelong. Six caregivers attended the meeting and three consented to participate in the study. The entire sample comprised of seven voluntary participants.

3.3 Data gathering and analysis

Data analysis in qualitative research is somewhat vague because it is not clear when data collection ends and analysis begins (De Vos, 2005; Sarantakos, 2000; Terre Blanche, Durrheim & Kelly, 2006). Data in the present study was gathered through individual semi-structured interviews using an interview schedule which was developed through reviewed literature. The interviews were audio taped for the purposes of accuracy in transcription. Before the interview began, all participants were asked to sign the interview and recording consent form (Appendix E). All participants were asked if they would like to be interviewed in English, Zulu or a combination of both languages. The latter was chosen by most participants and only a few chose to be interviewed in Zulu.

The interviews were then transcribed and translated simultaneously. Following this, the data was analyzed through thematic content analysis-the most basic and commonly used form of analysis in qualitative research (Green & Thorogood, 2009) which captures what appears real through the eyes of research participants (Henning, van Rensburg & Smit, 2004). After transcribing and translating each interview, the researcher read through each interview looking for themes that emerged in the data. After identifying the themes, the researcher once more read through the transcripts to identify data patterns that were

relevant to the research aims and questions. The themes were then coded and categorized in order to reduce the data into meaningful information.

3.4 Ethical Considerations

The aims of the present study were first explained to the project managers and a letter to request permission (Appendix B) was handed out in order to obtain permission. After gaining provisional permission, the researcher invited the caregivers to a meeting in the individual organizations in order to provide the caregivers with the details of the research. In the meeting the caregivers were told about the aims of the current study and the procedures that were going to be followed whilst conducting the study-such as recording, confidentiality, withdrawal, refusal to answer questions and debriefing. The caregivers were allowed to ask questions relating to the study at the meeting and at any time during the study. To further keep them informed about the study they were each given an information sheet (Appendix C) which contained information about the research and the researchers contact numbers to allow them access to the researcher should they have questions.

The caregivers were also given consent forms (Appendix D) where they had to indicate whether they 'give/do not give' consent to participate in the study. Before being interviewed the participants were again briefed about the aims of the study and reminded of their right to withdraw and refusal to answer questions that made them feel uncomfortable. They were also reminded about the recording and the intentions thereof and then asked to sign the interview and recording consent form (Appendix E). After the interview, participants were immediately debriefed to see if participants were not affected negatively during the interview. To ensure confidentiality and anonymity, the participants' names were replaced with an alphabet denoted by numbers in the transcripts and in the quotations made in the report.

The results of the study are presented and discussed in the next chapter.

CHAPTER 4: RESULTS AND DISCUSSION

4.1 Overview of results

Results will be discussed according to the structure of the interview schedule. The discussion will begin with discussing results from the personal/demographic information of the caregivers, followed by an analysis of their training and preparation and lastly the effects of caring on the health and well-being of the caregivers.

The current study consisted of eight participants; however the results are based on seven participants. One of the interviewed participants had to be withdrawn from the study as she did not fit the scope of the current research. She was an OVC caregiver and the focus of the current study was on HBC caregivers. The results were arrived at through thematic content analysis whereby the researcher transcribed and translated the recorded interviews. This was followed by reading through the transcripts to identify themes that emerged. The researcher read through the transcripts again to look for themes that related to the research questions. From the themes the results below emerged.

4. 2 Demographic information

Table 1 below gives a summary of the caregivers' demographical information of the participants, including gender, age, education level, home language and the participants' ability to speak English.

Table 1: Caregivers' personal information

Participant No.	**Gender**	**Age**	**Education level**	**Home language**	**Ability to speak English**
1	Male	21	Matriculated	Pedi	Fair
2	Male	25	Secondary	Zulu	Fair

			level		
3	Female	25	Secondary level	Xhosa	Fair
4	Female	37	matriculated	Zulu	Fair
5	Female	38	Secondary level	Xhosa	Poor
6	Female	44	Matriculated	Zulu	Good
7	Female	56	Primary level	Xhosa	Poor

The age of the participants ranged from 21 to 56 years with the mean age of 35 years. The ages of the participants are shown in the third column. Three of the participants were in the late to mid twenties. Two of the participants were approaching forty. Only one participant was in her forties. The other one was older than fifty years. Five of the participants in the sample were female. There were only two male participants and they were younger than thirty years.

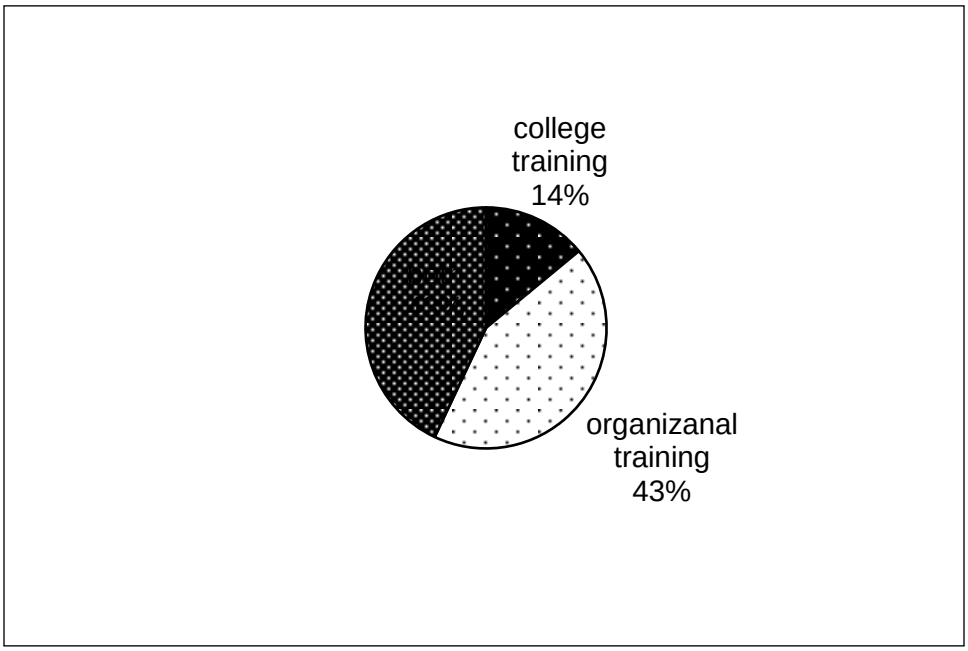
It is evident for the current study that the majority of caregivers are women as found in many other studies (UNAIDS, 2000; Barolsky, 2003; Mango, 2004; Marais, 2005; Orner, 2006; Opiyo, Yamano & Jayne, 2008; UNAIDS, 2008; Kangethe, 2009). In terms of male participation in caring, the current findings indicate that there still exists much disproportion and skewness in the gender ratio. This is consistent with the findings in the study conducted in Botswana at Kanye care program by Kangethe (2009). These findings are also consistent with the report by the UNAIDS (2008) that there are fewer men providing care in the home and home-based care programs. Also significant to note is that a majority of the caregivers fell between the ages of twenty and forty. This is contrary to a recent report in Botswana by Kangethe (2009) which found that 56% (N=46) of the participants in his study were over the age of fifty years and 34% (N=28) were older than sixty years. This contradiction highlights and emphasizes the statement by Barolsky (2003, p40) that '*the old and young, but almost always females, are taking on care-giving roles*'.

Three of the participants had passed grade twelve (Matric). Another three only had secondary education and just one participant had primary education only. Most of the participants in this study were literate and had previously received formal education unlike those in the study by Kangethe (2009) in Botswana at Kanye care program. Four (57%) of the participants reported that their ability to speak English was fair. Two (29%) of the participants reported that their ability to speak English was poor whilst one (14%) said that their ability to speak English was good. However all participants chose to respond in their home languages or a mixture of their home language and English.

4. 3 Training and preparation

All participants in this study had received some form of training in relation to their work as caregivers as illustrated in the figure below:

Figure 1: Caregivers' type of training institution



All the participants indicated that they had received training either through workshops provided in the organization where they were currently working (conducted by governmental departments), or college, or both institutions (college or organization).

Three (43%) of the participants reported that they received training both from their organization and college. Another three (43%) of the participants had only received training through the organization and one participant (14%) had college training only.

The duration of training varied greatly with the shortest being 3 days and the longest taking 12 months. The following table depicts the forms of training received by caregivers and their duration thereof.

Table 2: Summary of type of training and duration of training

Type of training	**Duration**	**Participants**
HIV/AIDS care/VCT	0-6 weeks	7 (100%)
Frail Care	3-6 months	4 (57%)
Nursing	3-12 months	3 (43%)
First Aid	0-6 weeks	1 (14%)
69 Days	7-12 weeks	1 (14%)
Other	0-6 weeks	2 (29%)

The results indicate that all the caregivers had received more than one type of training except for one caregiver that only trained for HIV counseling. The forms of training included HIV and AIDS care/VCT counseling, frail care, nursing, first aid and "69 Days" (a form of basic caregiver training lasting 69 days provided by the Department of Health), as well as child abuse, gardening, eye testing and administration. The latter forms of training i.e. child abuse, gardening, eye testing and administration were categorized as 'other' because the caregivers were currently not using them in their daily tasks. All caregivers were trained in HIV and AIDS care and/or VCT. Four of the caregivers had frail care and three had done a nursing course. There was one caregiver trained in first aid and one in "69 Days". In the 'other' category there were two participants.

The above results indicate that although caregivers are expected to have some form of training, there is no consensus when it comes to what they should be trained for and for

how long their training should be. This poses a problem in terms of task distribution. This opens up a gap for exploitation of the caregivers and unfair labour practices because there seems to be no clear job description. For instance, some of the caregivers in this study had this to say:

"…I also did the tests because at some point we were short of staff-so I also had to prick them as well. So I did the pre-counseling, then pricked them and did post counseling. Then there were also those for on-going counseling…If they have to start their treatment then you get them started."

Participant No. 6

"…I don't know because as people we do not work in the same manner. There are those that do not do their work. When they get to the patient, they just make them sign and when they get here they lie saying: 'oh, I found them all right'. When others go to that patient they find that they are bad. And when the family brings the claim here saying: 'hey! That person did not do anything when they came. They just made us sign. In actual fact, how do you conduct your services?' you see, now all of us are spoilt by one rotten tomato; you are all spoilt whereas you are doing your work well..."

Participant No. 5

4. 4 Caregivers' health and well-being

In order to respond to the research questions and aims of the current study; the following themes emerged from the content analysis.

4. 4. 1 Motivation

This question wanted to look at what motivates or inspires the caregivers in this study to do the work that they do. Brems (2001) identified 8 reasons why people choose to enter the helping profession. The reasons included:

1. The desire to help,
2. The desire to change the world,
3. The desire to create purpose and meaning,
4. The desire for self help,
5. The desire to control or tell others what to do,
6. The desire to share experience of recovery,
7. The desire to share personal insights or wisdom and
8. The desire for financial freedom and status (Brems, 2001; p 10-15).

Other reasons or motivation to care include compassion, self interest, a sense of religious duty, the need to control the disease and the hope for a paid income and incentives offered by volunteer programs (UNAIDS, 2000). And for many it is because they themselves are infected or affected by HIV/AIDS (UNAIDS, 2000; Wight, LeBlanc & Aneshensel, 1998; Pirraglia et al, 2004).

For the current study, the following motivation themes emerged:

Table 3: motivational themes

THEME	**CATEGORY**	**NUMBER OF PARTICIPANTS**
Desire to help	• Many people don't know what to do or where to go for help when they are sick • There is little help (fewer	4 (57%)

	helpers) in the community	
Love for people	• Love working with people	4 (57%)
Interest in people and their well-being	• Having the desire to see people healthy and well	3 (43%)
Affected by HIV/AIDS	• Witnessing family members or relatives die of AIDS • Have friends and family living with HIV • I am also HIV positive	3 (43%)
Job opportunity	• One day I will become a nurse • The little stipend that I get makes a difference-it is an income • It is better than sitting at home and doing nothing	3 (43%)
Calling from God or Talent	• I am good at what I do (caring) • God wanted me to do this	3 (43%)
Inspired by others	• Having a relative that does the same work • Inspired by other professionals such as nurses and doctors	3 (43%)
Making a difference	• Making a difference • Just being there even if there's nothing to offer • Talking to people and encouraging them	1 (14%)

	• Sharing information	
Being loved and appreciated	• Love from patients and their families • People coming back to say thank you • People noticing the importance of the work of caring	2 (29%)
Sympathy or identification with patients	• Feeling sorry for the sick people • I could also feel sick one day, just like them (patients)	2 (29%)
Exposure to trauma	• Helping or caring for a relative that had a near to death experience	1 (14%)
Getting away from personal stress	• Getting away from stress • To forget your own problems	1 (14%)

Most of the participants were motivated by various reasons. The most common reasons were the desire to help and love for people with four of the seven participants mentioning these reasons. Three of the participants alluded to job opportunity, calling from God, interest in people and affected by HIV/AIDS as their motivators. Inspiration from a relative was given as a motivator by two participants. Sympathy and/or identification with the patient were also reported by two participants. Two other participants were motivated by being appreciated and/ or being loved. Making a difference and traumatic experience were cited by only one participant. The above findings suggest that although most of the caregivers are motivated by various reasons they, however seem to be mainly motivated by altruistic reasons rather than selfish ones.

Some of the motivating reasons found in this study are consistent with those found in other writings (Brems, 2001; UNAIDS, 2000; Wight, LeBlanc & Aneshensel, 1998; Pirraglia et al, 2004). Inspiration by relatives and trauma experience were the only motivational reasons not cited elsewhere in the literature reviewed. This indicates that caregivers are motivated by more or less the same reasons. The quotation below gives a clear summary of the motivation themes discussed above:

"I got motivated because in my family-where I'm married, my brother-in-law's child once got sick-the year was 2000; before I knew this thing of HIV...The child has to go to the clinic even her hair seems to be showing the sun... She (the mother) did not agree until the person died! I understood then that I would take the decision to go to the clinic and request to volunteer…I volunteered for 1 year not expecting any incentive; just helping the community! After 1 year, then I received a stipend. It's just the love for it, I love it because I work with people-helping them- encouraging them to eat their treatment…I love this job a lot sister, please forgive me! Even now, now as I am here there is nothing that bothers me. I love my job! When they would say : ' at the kitchens this-that; there's no salary here!' I'd say: 'I want this 1 that God loved for me to work'…Well, I'm trying to say that I am satisfied with my work, it does not make me weary in any way. It becomes painful only when you arrive and see that the condition eish! They are sick! It's not…I mean it's not nice when you see 1 of yours in a bad condition".

Participant No. 7

To further explore motivational reasons, participants were also asked to mention things they liked about their work. In terms of likes participants had to say what it was that they enjoyed or made them happy in their work. The following themes were identified from the interview responses:

- Witnessing a patient recover: This was reported by 3 (43%) participants.
- Feedback and appreciation (Patients coming back to say thank you or reporting that the advice they received worked or just keeping the caregiver updated about their condition): It was reported by 4 (57%) participants.
- Acknowledgement and recognition (When people in general notice their work and show them some respect): 3 (43%) participants reported this.

- Working with people: It was mentioned by 3 (43%) participants

It is clear that for participants in this study appreciation and acknowledgement meant a great deal. This goes on to show that is it the small things that really matters and make a difference for the caregivers. This further provides evidence that the participants are genuinely motivated by love and the welfare of others. This is what another respondent said:

"***What makes me happy a lot sometimes is when somebody appreciates my help because they recognize the help that I am giving and that makes me very happy. That some people acknowledge what I am doing, that makes me happy for people to appreciate the help that I am bringing to them. When I wake up in the morning I know that certain people appreciate what I am doing that's what makes me happy and makes me say: 'let me wake up and go to work'".***

Participant No. 2

4. 4. 2 Benefits

Participants were asked to mention things that they benefit or gain from their work as caregivers. Six of the seven caregivers mentioned that they gained skill and experience from their work. The skills gained included nursing skills, problem-solving skills and communication skills. Five of the participants said that they gained knowledge and information from the training they attend not only about HIV and AIDS but about health in general. One respondent had this to say:

"…a lot of information on how to handle different situations. From now I know many things from doing this job before I didn't know-I had no idea. Previously I used to do things that were done in the township. For instance when someone was burnt [Giggles] you'd smear them with toothpaste. So now I know that I have to used ice or cold water."

Other participants (3 participants) saw the opportunity towards a professional career as a benefit because it meant a step towards progress. Others (2 participants) found fulfillment and relief from their work. Empowerment was reported by two participants as a benefit as some found that their work gave them confidence. Figure 2 and Table 4 below provide a summary of the reported benefits in the current study as well as the relevant themes.

Figure 2: Reported benefits

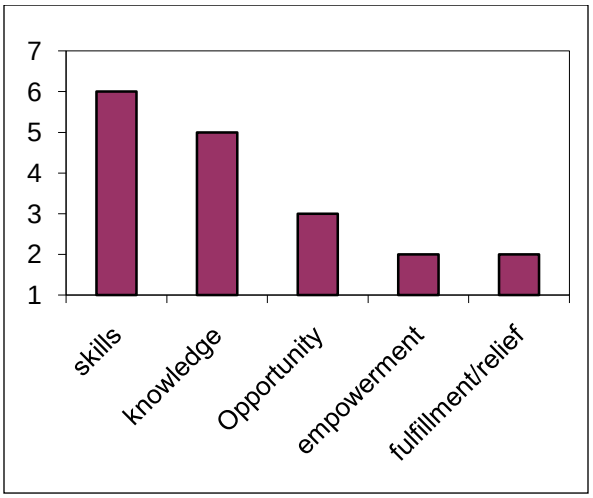


Table 4: Benefit themes

THEME	CATEGORY
Skills	• Communication skills • Problem-solving skills • Nursing skills • Helping skills • Experience
Knowledge	• Education • Training • Learning • Gaining information

	• Gaining knowledge
Opportunity	• Chance to study further • Progress towards a profession • Chance to improve • Having something to do
Empowerment	• Gaining confidence • Facing things that one couldn't face before
Fulfillment/Relief	• Satisfaction & contentment • Joy • Liberation • Healing

These findings are contrary to the findings by McClausand and Pakenham (2003) who found that most of the themes in their study related to personal issues and that the most reported benefit was that of personal growth. In the current study however, only 2 of the participants in the sample reported personal growth as a benefit. The most reported benefits in the current study relate more to intellectual development as opposed to emotional interpersonal benefits. Important to note as well is that the benefits reported in the current study and the one by McClausand and Pakenham (2003), both exclude monetary gains.

4. 4. 3 Challenges

This section looks into the challenges that caregivers in this study generally face in their line of work and lives. The various challenges are discussed below.

4. 4. 3. 1 Lack of materials

Over half of the participants (4) faced the challenge of lack of materials such as masks, gloves, bandages and other protective wear. It is obvious from these findings that caregivers find their work to be dangerous and unsafe. With over half of the participants reporting a lack of materials; this raises serious issues about the well-being of the caregivers. This clearly indicates what was observed by Marais (2005) that '*home- and community-base care might reduce the cost of care to the health care system (and state) but does so in the main by displacing the costs on to caregivers…'* (p65). This means that caregivers also pay by risking their lives too.

"Things like disposable nappies and at times you find that there is no food in that house-hold. Savlon (antiseptic liquid), for cleaning the bed sores because they often smell bad. Mostly when they are bed ridden or terminally ill they have bed sores and do all these things-just a little Savlon to pour in the water and wash them. And bandages, gloves; these things are often short-a lot! And you find that at times we have to wear plastics on our hands."

Participant No. 4

This also raises questions about the supply and distribution of resources, which unfortunately is not within the scope of this research.

4.4.3.2 Fear of infection

Linked to the above mentioned challenge, is the fear of infection especially that of TB. Four participants reported this as a problem they face. The quotation below captures those sentiments.

"And another thing, when it comes to the patients, there are those that have TB. When you visit those patients you find that maybe you don't have masks then as you breathe-I mean some take the treatment but others stop and if you stop the virus gets stronger in

the patient. You find that you have chest pains-I mean myself, I get chest pains. You know, I can feel that I am not well.”

Participant No. 6

4.4.3. 3 Lack of interest from family members

Another challenge that caregivers in this study faced was that of patients living alone or those whose family did not partake in the caring of the patient as this left them with having to do tasks beyond caring such as providing for them. Although not so explicit, these results are suggestive of a subtle form of discrimination from patients' families. Although it may be towards the patient it however affects the caregiver because they have to take on tasks which family members are meant to do. For example:

“So I quickly took them to hospital because they were no longer eating and were living alone-had no one in the house. He lived in a 4 roomed house all alone…So the neighbours informed me that he was no longer eating and had stopped taking his treatment. When I last went to visit him I realized that he was getting worse every time then I called the ambulance and took him to hospital…So I called to check on how he was doing and to also arrange for him to be taken to a hospice. So they said we have to get his relatives but they are nowhere to be found…These are the challenges we come across. Who is going to care for him? He too is not happy to go back to the house because when he is too sick there is no one to help him because he is alone. So this causes you intense pain because you end up doing work that you are not supposed to do-things that are supposed to be done by relatives and family members.”

Participant No. 6

This difficulty was reported by 3 participants. Moreover, two of the participants that reported family problems they also reported that they received little or no from their own

families. That ranged from no help with house-hold chores as well as verbal and emotional abuse.

4.4.3.4 Rejection by patients

Three of the participants had the problem of being rejected by patients that refuse to be helped. This seems to rise from patients' dissatisfaction and denial, for example:

"… Sometimes there are groceries for the orphanage-for orphans and vulnerable children… so the sister [nurse] allocates us those food parcels one for each patient in home-based care. So the next time you go to the patient and you have no food parcel… some of them become angry and others tell you to never come back."

Participant No. 2

"…you find that that person (patient) does not welcome you…when you get there s/he tells you that s/he is not sick…or tells you that s/he doesn't want your help"

Participant No. 3

4.4.3.5 Poor funding

Close to that was the issue of poor funding which led to the lack of financial incentives. In some instances the caregivers had to wait for long to receive their stipends due to inconsistencies, whilst some found that the stipends were not enough to meet their needs. The issue of financial constraints or hardships is a common feature among challenges that face caregivers (Barolsky, 2003; Kangethe, 2009; Levin, 2006; Marais, 2005; Simpson, 2006; UNAIDS, 2000 & UNAIDS, 2008). This goes to show that the economic impact of HIV and AIDS can never be underestimated.

4.4.3.6 Heavy work-load

Too much workload was also another challenge faced by three of the caregivers in this study. This is also consistent with findings from other studies (Wight et al, 1998 & Simpson, 2006). Although the other participants mentioned having a lot to do but they seemed to be coping well because they had better time management skills and were able to separate their work from their personal lives, whilst one struggled to manage time to an extent that they were exploited by patients.

4.4.3.7 Loss due to death

Loss due to death was challenging factor for two participants. One participant reported losing a patient just a week prior to the interview. One participant still had unresolved issues around her personal losses.

4.4.3.8 Work related problems

Two participants had work related problems. The one participant had challenges regarding work policies. For the other participant the problems ranged from claims of exploitation by management, lack of transparency and poor relationship with colleagues.

A summary of the challenges faced by the caregivers in this study are displayed below:

Figure 3: Summary of challenges and the number of respondents per challenge

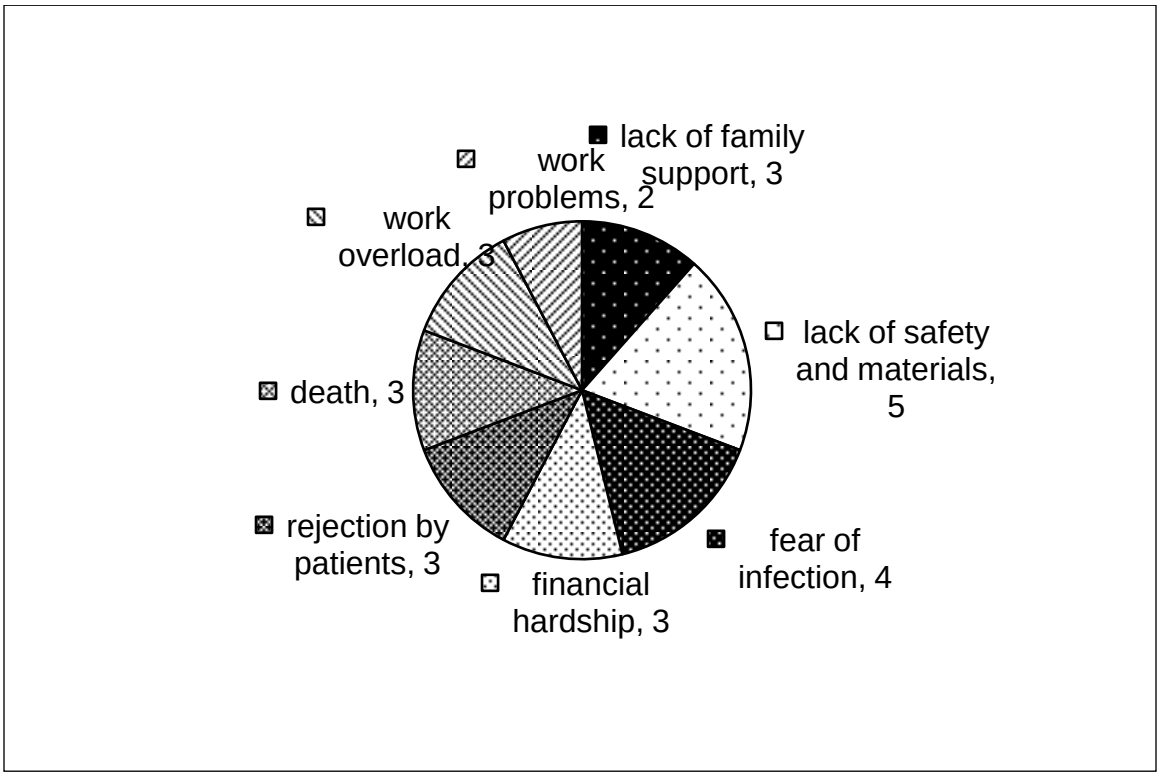


Table 5: Summary of themes of challenges faced by caregivers

THEME	**CATEGORY**
Lack of family support	• Patient living alone • Patient's family not involved • No help with caregivers' domestic chores
Lack of safety and materials	• No materials e.g. gloves, masks, bandages, Savlon • No protective over-wear e.g. aprons • No safety/protection in the field • Fear of infection especially TB
Financial hardships	• Little money • Waiting too long for stipends
Rejection by patients	• Denial of sickness

	• Ignorance • Refusing help and treatment
Death	• Loss of a patient • Loss of a loved one
Work overload	• Too many patients • Working overtime • Too much to do • No time to rest • Exploitation by patients
Work problems	• Policy constraints • Clashing practices • Competition • Conflict with colleagues and management • Exploitation and lack of transparency

4.4.4 Aspects of caring

This section is subdivided into physical, emotional and spiritual aspects of caring. The aim was to look at both positive and negative effects of caring on the health and well-being of the caregivers.

4.4.4.1 Physical aspect

Two participants reported that their work had positive effects for them physically. One reported that they were sleeping better and had also gained weight. The other one said that with the knowledge gained they were now taking better care of themselves. The participant mentioned that he stopped smoking and had reduced alcohol consumption by only drinking occasionally. Another three of the participants said that their work had no

effect on their health. Even after probing there were no signs of negative or positive effects. One respondent, however, mentioned having head and body aches but denied it being related to her work. This may be true in relation to the contents of her work but could be as a result of work relations as indicated in the statement below:

"I won't speak badly about those people-my patients. I work very well with them. They don't give me stress! I've never had stress that comes from them, to an extent that I wish I could stay with them. As soon as I enter this yard eish! My spirit changes and I think 'oh my God, I've arrived at this place!' ...when you arrive feeling happy you come across things you didn't expect…just as you arrive, then it's on!"

Participant No. 5

The last two participants after probing admitted to being negatively affected by their work. Their symptoms included sleeplessness/disrupted sleep, tiredness, neglect of other duties, pains on neck, shoulders and chest, thinking too much and not thinking properly, tearfulness, restlessness. These symptoms are suggestive of carer burnout as listed by the UNAIDS (2000). The above results although not conclusive suggest that caregivers are not greatly affected by their work physically. Although other studies have shown that most caregivers are physically affected by their work (), the explanation for the difference in the current study could be that most of the participants were younger compared to other studies that mainly comprised of elderly participants for instance Kangethe (2009), Levin (2006), Knodel, Saengtienchai, Im-em and VanLandingham (2000) and Kespichayawattana and VanLandingham (2002). This is an indication for further research into the differences.

4.4.4.2 Emotional aspect

In this sphere, upon analysis, one participant seems to have been positively impacted by their work as it appears to have boosted their self-esteem and given them confidence to face their anxieties:

"…this thing of care giving has given me the power to realize that your job is your job…now I no longer have that fear. No matter how injured a person may be I no longer have that fear of facing a person like that…I can now face the things I used to fear."

Participant No. 1

Two of the participants seemed to not be emotionally affected by their work. Four of the participants were emotionally affected in a negative way. Two of the participants strongly displayed feelings of loneliness as captured in the following statements:

"There's no one to tell because you've migrated here; you are not from here. Who are you going to tell your problem to? What will that person say? I will tell you my problem but you don't know me so it's all the same let me rather call on Jehovah…when I have a problem, my husband works, I close the door lift up my hands and call upon Him (God)."

Participant No. 7

"The issue now is that I no longer have sisters. When my sisters were still alive; if there was something troubling I would talk to them…even when I'm just sitting I realize that there is no one to guide me anymore"

Participant No. 5

Other emotional effects included irritability, feelings of inadequacy and helplessness. Two participants also reported a disruption in their relationships.

"eish…I'm sorry to say, since I got infected with the virus um I think the way we are living in the house; we are just living. Like even when things go wrong in the relationship there is that expectation that: 'you'll understand because you can't go anywhere, even if I abuse you. You are sick, where will you go?'…So there is no

support at home-at all-at all! To an extent that I keep quiet at home when I have a problem.

Participant No. 4

It is evident that the caregivers are greatly affected emotionally by their work. This is in line with other previous findings such as those by Felemengas, (2005), Knodel, Saengtienchai, Im-em and VanLandingham (2000), Pirraglia et al (2004), Simpson, (2006) and UNAIDS (2000).

4.4.4.3 Spiritual aspects

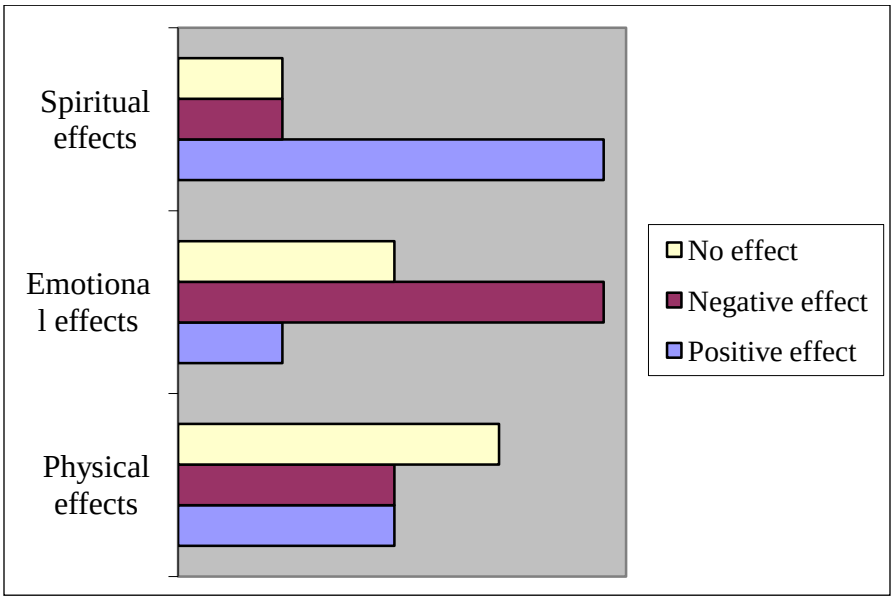
Six of the seven participants made reference to God. Only one did not talk about faith. Most of the participants (4) were positively affected as they mostly found comfort in prayer, reading the bible, praising and worshiping and going to church. However, two of them indicated that at times they don't go to church due to having a lot of work. Although this is not a matter often researched, the current study shows that spirituality plays an important role in the life of the caregiver. Over half of the participants reported being affected positively by taking part in faith-based activities such as praying and going to church. This suggests that caring to some extent draws caregivers' closer to their spirituality.

According to the UNAIDS (2008) anecdotal evidence from faith-based organizations showed that the following two themes are common:

- Taking time for prayer, reflection and devotion
- Seeing the church as a source of spiritual nourishment for the staff (caregivers)

The figure below gives a summary of the results of the aspects of caring

Figure 4: Caring effects



Important to note is that three of the caregivers that reported being positively affected or not affected at all were between the age of 20 and 30, and two of those were male. This suggests that gender and age play a role in caring. The former was coined by Fredriksen-Goldsen (2007) who found that being female was greatly associated with distress in care-giving.

4.4.5 Coping strategies

This section looks into the caregivers' ways of coping with challenges. The themes are given in the table below

Table 6: Coping strategy themes

THEME	CATEGORY	PARTICIPANTS
Self	• Doing domestic chores • Watching television	6 (86%)

	• Listening to the radio • Reading –bible or work related material • Spending time alone • Sleeping • Taking a bath	
Colleagues	• Talking to partner • Talking to other colleagues	5 (71%)
Project managers/ Social worker	• Case management • Grant applications • Patient transfers (to Hospice) • Food parcels	4 (57%)
Friends	• Talk to friends	2 (29%)
Family	• Talk to husband • Talk to relatives	2 (29%)
Church counselors	• Counseling at church	1 (14%)
Patients	• Befriending patients and talking to them whilst visiting them	1 (14%)
Clinic	• Pain medication	1 (14%)

Six of the participants in this study relied on themselves for emotional support. They used various strategies to combat emotional stress such as doing domestic chores, watching television or listening to the radio, reading and spending time alone, sleeping or taking a bath. The second most commonly used form of coping strategy was support from colleagues. Five of the respondents reported that they got support from talking to their colleagues. In this regard most of the participants reported that they mainly spoke to their work partners as they usually work in pairs. Four of the participants also mentioned that they received support from the project managers and/ or social worker; however much of that support was mainly for case management purposes which in turn helped the patients

more than the caregivers themselves. Friends and family were also used by fewer participants (2) for emotional support. Only one participant used some form of formal counseling from church counselors. One participant even went to the extent of talking to patients about their problem. The clinic was accessed by only one caregiver for medical purposes.

These results indicate that caregivers have little support. All participants reported that they had no debriefing or supervision sessions from their organizations or elsewhere. These results are consistent with the findings by Simpson (2006), which revealed that caregivers were not receiving sufficient psycho-social support to help them cope. Even family and friends are not available for support as a large portion (5) of the participants had migrated from rural areas and had fewer friends and relatives in Johannesburg.

4.5 Discussion

This study has shown that the majority of caring is still borne by women as five of the participants in the sample were females. This is consistent with findings in previous studies and reports (UNAIDS, 2000; Mango, 2004; Marais, 2005; Orner, 2006; Opiyo, Yamano & Jayne, 2008; UNAIDS, 2008; Kangethe, 2009). This indicates that there still exists a skew in the proportion of gender in caring as evident in other findings (UNAIDS, 2008; Kangethe, 2009). The current study does not provide reasons for this gender disproportion; however, according to the UNAIDS (2008) this may be due to under-reported cases of males providing care because gender stereotypes and limited studies focusing on the roles of males in care giving.

Five of the participants were between the ages of twenty and forty, with only one participant above forty and fifty respectively. This is contrary to previous reports which state that a majority of caregivers are elderly people between the ages of 50-60 and above (UNAIDS, 2008; Kangethe, 2009). The findings concur with the statements by Webb-

Robinson and Wilson (2008) who claimed that most caregivers are in their child bearing age.

Also important to note is that all the participants in this study had received formal learning. Three participants had matriculated and had post matric education. Another three only had secondary education and just one participant had primary education only. This is contrary to the findings by Kangethe (2009) in Botswana where a large proportion of the sample had never been to school (35%) or had only received primary education (39%). This could be attributed to the fact that most of the caregivers in his study were older whereas in the current study a majority of the caregivers were younger than forty and only one was above fifty. Furthermore, the participants in this research had received training in relation to their work. All but one had received more than one type of training. This suggests that caregivers in this study are hungry for knowledge and take their work seriously. This also challenges the misconceptions held by many about the literacy levels of caregivers. What, however emerged is that there is no consensus when it comes to what caregivers should be trained for and the duration thereof. Interestingly, the eldest participant had the lowest level of education but had the most training.

Participants in this study were mainly motivated by altruistic reasons such as the desire to help and love for people. Over half of the participants cited these as their motivators. Others saw their work as a response to God's calling while others were responding to personal experiences of HIV/AIDS. Those that saw care-giving as an opportunity for a job were more driven by the desire to make a career rather than monetary gains. It is quite apparent from the results in this study that caregivers are motivated mostly by reasons similar to those found in other reports.

The most reported benefits by the participants were not consistent with other findings. They were intellectually rather than emotionally based indicating the determination of the caregivers and the meaning they attach to their work. It appears they view care giving as a means to career development and an opportunity to get an education. This makes sense

because a majority of the participants in this study were migrants from rural areas who had come for better job opportunities. What is also evident is that the caregivers value being acknowledged and appreciated.

It is also clear from the findings that most caregivers were not negatively affected physically by their work but those that were, reported many signs of burnout. In the emotional sphere, this is where a majority of the caregivers were negatively affected and further displaying signs of burnout. However many of the caregivers revealed that their work had brought them closer to God and their spiritual beings as most of them partook in faith-based activities. Results also indicate that caregivers have little support from their organizations and family. Most of them rely on themselves and each other for support. This is an indication that more still needs to be done to support caregivers. Furthermore, extensive research still needs to be conducted with a larger sample to look into the positive and negative effects of caring. Although the current study attempted to do that the sample was too small and the findings cannot be generalized for all caregivers.

Chapter 5: CONCLUSION

5.1 Summary of the study

The current study has shown that most caregivers are still women falling in the 20 to 50 years age range. According to the results, caregivers are motivated by various reasons almost similar to those cited in Brems (2001) and the UNAIDS (2000). The results have indicated that all caregivers had received formal education and trainings related to their work. It is however, clear from the results that the trainings received by caregivers are not uniform or standardized implying that caregivers do not receive the same type of training. It also emerged that there is no consensus about the period of training a caregiver should receive. This suggests that some caregivers may be better trained than others and therefore lead to different work practices and opening gaps for exploitation.

Results show that the caregivers in this study face challenges similar to those faced by other caregivers. However, amidst the challenges faced by the caregivers they still remain resilient with only 29% (2 participants) of the caregivers displaying signs of physical burnout. Caregivers in the present study were mostly negatively affected emotionally by their work; however the experience seems to have brought them closer to God and improved their spiritual lives. Most of the caregivers in this study indicated that they found most of their support in faith based activities.

5.2 Limitations of the study

This study used a very small sample of caregivers and therefore the results cannot be generalized over all caregivers. Moreover, the study was context specific, i.e. peri-urban area-implying that the results may only apply to caregivers in similar contexts. The current study did not align itself to any theoretical framework which may have probably guided the research and produced different results. Although the present study lacked a theoretical framework, it should be noted that the study was based on reviews of prior research which then accounts for this shortcoming.

5.3 Recommendations

The following recommendations are made based on the findings of the current study. Recommendations are made for the caregivers and their individual organizations as well as for future research.

5.3.1 Recommendations for the caregivers and organizations

- Given that most of the caregivers depend on themselves for emotional support, they may benefit from trainings in self-care and self-awareness skills

(as described in Brems (2005)) to help them care better for themselves and prevent caregiver burnout.

- Another strong source of support for the caregivers is colleagues therefore forming a caregiver support group may be beneficial in helping the caregivers share their experiences.
- Continuous and consistent supervision and debriefing sessions from the organizations are necessary to up and maintain caregiver morale.
- Consistent supply of safety materials such as masks and gloves may help alleviate fears of infection among caregivers.
- It would be beneficial for the organizations to have a standardized basis of training requirement in terms of the type of training and duration of training to avoid differing work practices and exploitation.
- Providing equal opportunities to caregivers may also help reduce work related grievances among the caregivers.

5.3.2 Recommendations for future research

- Further cross-sectional research into negative and positive effects of caring still needs to be done with larger samples of caregivers.
- It appears as though the negative effects of care giving do not differ much, future research should look into investigating the positive effects of caring.
- Focus should be given to exploring religious or faith based responses by caregivers to the effects of caring. That is, to explore the role of religion in care giving.
- Future research could also look into the roles of gender and age in caring
- Future research should also look into the issue of the supply and distribution of work materials in community projects and how that affects caregivers and their ability to care.

Appendix A: Interview Schedule

Personal Information

1. Age
2. Gender
3. Home Language
4. Highest Level of Education
5. English Ability-speak, read, write.

Training & Preparation

6. What type of training have you done in relation to your work as a caregiver?- formal v/s informal training?
7. Where did you train? E.g. University, Technickon, College etc
8. How long was your training for? Briefly describe the nature of training
9. In what language did you receive your training?

Health & Well-being

10. What motivates you as a caregiver for people living with HIV/AIDS?
11. What makes you happy about your role?
12. How would you describe your current state of health and well-being?
13. How do you tell that your health and/ or well-being are compromised (weak)?
14. What worries you about your line of duty?
15. How do you deal with day-to-day challenges (difficulties)?
16. Where do you go to for emotional (feelings) help and support?
17. What is your experience of the type of service you get?
18. What do you do to relax and unwind (calm down)?

Appendix B: Letter of request



UNIVERSITY
OF THE
WITWATERSRAND,
JOHANNESBURG

School of Human and Community Development
Private Bag 3, Wits 2050, Johannesburg,
South Africa
Tel: (011) 717-4500
Fax: (011) 717-4559

Dear Sir/Madam

Request for permission to conduct research

I hereby request permission to conduct research at your facility with caregivers of people living with HIV/AIDS for the purpose of obtaining a Master's Degree in Clinical Psychology at the University of the Witwatersrand. The research title is: 'Perceptions of health and well-being among caregivers of people living with HIV/AIDS'. The study aims to explore the relationship between caring and the health and well-being of caregivers of people living with HIV and AIDS. The study also aims to evaluate the availability, accessibility and efficiency of support received by home-based caregivers.

Participation is voluntary, and no person will be advantaged or disadvantaged in any way by choosing to participate or not participate in the study. Participants will be asked to sign a consent form for their participation in the study. Information will be gathered in the form of individual recorded interviews lasting approximately one hour. All interviews and transcripts will be kept in a safe place to ensure confidentiality, and all identifying information will be excluded in the report. Participants may refuse to answer any questions they feel uncomfortable with and may choose to withdraw from the study at any point should they feel unable to continue participating.

Results of the research will be presented in a report that will be kept at the university.

Kind Regards

Sindile L. Shobede
Clinical Psychology Student
0722649658/0119260630

Dr. Mambwe Kasese-Hara
Supervising Psychologist
0117174552

Appendix C: Participant Information Sheet



UNIVERSITY
OF THE
WITWATERSRAND,
JOHANNESBURG

School of Human and Community Development
Private Bag 3, Wits 2050, Johannesburg,
South Africa
Tel: (011) 717-4500
Fax: (011) 717-4559

Dear Caregiver

My name is Sindile Shobede; I am conducting research for the purpose of obtaining a Master's Degree in Clinical Psychology at the University of Witwatersrand. I am interested in studying the relationship between caring and the health and well-being of caregivers of people living with HIV and AIDS and also evaluating the availability, accessibility and efficiency of support received by the caregivers. This research will add onto current knowledge about the impact of care-giving among caregivers of people living with HIV/AIDS, particularly in the township area.

Participation in this study is voluntary and you will not be advantaged or disadvantaged if you choose to or not to participate. Your participation will entail an individual interview lasting approximately an hour at a time that suits you. Debriefing will take place after the interview. The interview will be recorded to ensure accuracy. The recorded information and transcript thereafter will be kept safe in a private locker to ensure privacy and confidentiality. All identifying information will be removed in the research report. On completion of the research all tapes and transcripts will be completely destroyed. Prior to participating, you will be asked to sign a consent form for participation in the study, permission to record the interview and quote some of your responses. You may refuse to answer questions that make you uncomfortable and you may withdraw from the research at any point should you feel unable to continue.

Results of the research will be presented in a Report that will be kept in the University library. A copy of the summary of findings with recommendations will be given to the participating organizations.

If you wish to participate in the study please indicate in the participant informed consent form and leave the form sealed in the provided envelope with the Manager of the Community Project.

Kind Regards

Sindile L. Shobede
0722649658/0119260630

Appendix D: Participant Informed Consent Form

I _____, give/do not give consent to the researcher of "Perceptions of health and well-being among caregivers of people living with HIV/AIDS" to use my services as a volunteer in order to successfully fulfill the aims of the research.

I am aware of the research aims and the ethical codes that will be followed and have no queries or disapproval. I am aware that participation involves a recorded interview and I am only entitled to a copy of my session should I need it. I am also aware that the recorded interviews are strictly private and confidential and should be handled as such.

I give my consent voluntarily without threat of punishment or promise of special rewards. I acknowledge that I am permitted to withdraw as a volunteer at any time or refuse to answer any questions I am uncomfortable with and that my withdrawal or refusal will not result in any repercussions whatsoever.

I acknowledge that the researcher will be available to answer any questions during the research and I have received the contact details of the researcher.

I have been given a copy of the participant information sheet.

Signature: _____ Date: _____

Appendix E: Interview & Recording Consent Form

I _____ consent to being interviewed by Sindile Shobede for the research titled "perceptions of health and well-being among caregivers of people living with HIV/AIDS." I understand that:

- Participation is voluntary,
- I may refuse to answer any uncomfortable questions or withdraw from the study at any point,
- The interview will be recorded and part of my responses may be quoted
- My responses are confidential and no information identifying me will be included in the research report.

Signature: _____ Date: _____

Appendix F: Letter of permission-Bophelong Community Project

BOPHELONG-EMPILWENI NEW-LIFE COMMUNITY PROJECT

152 NKANYAMBA STREET
MQANTSA SECTION
TEMBISA
1632
011 924-4898
013-499 NPO
2010.01.27

Dear Sir/Madam

We acknowledge receipt of your letter requesting permission to conduct research in our facility. We are glad to offer you (Sindile Shobede) the opportunity to conduct research in our Project on caregivers of people living with HIV/AIDS for the purpose of obtaining a Master's Degree in Clinical Psychology.

We are looking forward to welcome you in our Project and hope that we can achieve your degree.

Best regards

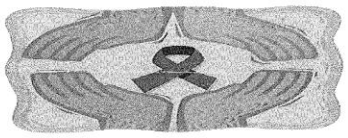
.....
P. Director

BOPHELONG-EMPILWENI NEW
LIFE COMMUNITY PROJECT
(011)924-4898
072 683 1738

Appendix G: Letter of permission-Helping Hands Home-based Care

Helping Hand Home based Care
NPO No: 017-606
PBO No: 930025351 in terms of
Section 18 (A) and Section 30
Of the Income Tax Act

P.O Box 135
Tembisa
1628
168 Esangweni Crèche
Tembisa
1628. Telefax: 011 – 925 – 6674



Vision

To combat HIV/AIDS and to provide support to Orphan and Vulnerable children in our community

11th February 2011

Dear Sir/Madam

The above mentioned organisation has allowed Sindile Shobede to interview the Care-Workers in October 2010 for her research project. It was an opportunity for the organization to participate in the study to help her fulfill her requirements for her Master's Degree in Clinical Psychology.

We appreciated her presence in our organization and widh her success in her career.

Kind Regards

D Vilakazi

D.Vilakazi (Project Leader)

HELPING HAND
HOME BASED CARE
168 ESANGWENI SECTION
TEMBISA, 1632
TEL: (011) 925-6674

***(Board of Directors)**:Mr. A.Masenya (Chairperson),Mr.M.Mafika (Deputy Chairperson),Mrs.S. Shikhwambane (Secretary)),Mr. M.Mogano (Deputy Secretary),Mr.T.Ramaogopa (Treasure)Mrs.S.Mndawe(Additional Member), Mrs.A.Maleka (Professional Nurse/Supervisor),Mrs.D.Vilakazi(Project Leader).*

Appendix H: Ethics clearance certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (NON MEDICAL)
R14/49 Shobede

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER H100 314**
PROJECT	Perceptions of health and well being among caregivers of people living with HIV/AIDS
INVESTIGATORS	Ms S L Shobede
DEPARTMENT	Psychology
DATE CONSIDERED	12.03.2010
DECISION OF THE COMMITTEE*	Approved Unconditionally
NOTE:	

Unless otherwise specified this ethical clearance is valid for 2 years and may be renewed upon application

DATE 25.03.2010 **CHAIRPERSON** (Professor R Thornton)

cc: Supervisor : Dr M Kasese-Hara

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.

I/~~We~~ fully understand the conditions under which I am/~~we are~~ authorized to carry out the abovementioned research and I/~~we~~ guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/~~we~~ undertake to resubmit the protocol to the Committee. I agree to a completion of a yearly progress report.

Signature

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Reference List

Abrahamsohn, D. A. (1994). *The dissemination of knowledge between medical and non-medical staff in a hospital setting as a means of preventing AIDS infection of hospital workers*. Johannesburg: University of Witwatersrand

Barnett, T & Whiteside, A (2002) Individuals, households and communities. In *AIDS in the 21st century: Disease and globalization.* New York: Palgrave Macmillan

Barolsky, V. (2003) (Over) extended. *AIDS Review2003*. Pretoria: University of Pretoria Retrieved September, 17, 2008 from http://www.csa.org.za

Brems, C. (2001) Basic skills in psychotherapy and counseling. USA: Brooks/Cole Thomson Learning, Inc.

Department of Health (2007) HIV&AIDS and STI strategic plan for south Africa 2007-2011. Pretoria: South Africa. Retrieved June, 29, 2009 from http://www.doh.gov.za/docs/hivaids-progressrep.html.

Department of Health (2008) Social tract: module on caring for the caregiver. In *Training manual: Operational plan for comprehensive HIV and AIDS care, management and treatment for South Africa.* Pretoria: Pretoria University Retrieved June, 29, 2009 from http://www.doh.gov.za/docs/hivaids-progressrep.html.

D'Cruz, P. (2004) Family care in HIV/AIDS: Exploring lived experience. New Delhi: Sage Publications India Pvt. Ltd.

Family Caregiver Alliance (2005) Selected caregiver statistics. San Francisco. Family Caregiver Alliance. Retrieved February, 26, 2010 from http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=439

Felemengas, M. (2005) *Caregiver experiences and perceptions of the effects of stroke on the family within the South African context.* Johannesburg: University Witwatersrand

Fredriksen-Goldsen, K. (2007) HIV/AIDS Caregiving: Predictors of well-being and distress. *Caring with pride*. Pp53-73. The Haworth press, Inc. Retrieved November, 5, 2010 from http:// o-web. ebscohost. com. innopac. wits.ac.za\ehost\pdfviewer?hid=109&sid=d6370258-e7f9-433f-b93d-274b3128fafc%40sessionmgr112&vid=6

Green, J & Thorogood, N. (2009) Qualitative Methods for Health Research. (2nd Ed) London: Sage publications Ltd.

Held, V. (2006) The ethics of care: Personal, political and global. New York: Oxford University Press, Inc.

Henning, E., van Rensburg, W. & Smit, B. (2004) Finding your way in qualitative research. Pretoria, South Africa: Van Schaik Publishers

Kangethe, S. (2009) Critical coping challenges facing caregivers of persons living with HIV/AIDS and other terminally ill persons: The case of Kanye care program, Botswana. *Indian Journal of Palliative Care*. Retrieved February, 25, 2010 from: http://www.jpalliativecare.com/text.asp?2009/15/2/115/58456

Kespichayawattana, J. & VanLandingham, M. (2002) Health impacts of co-residence with and caregiving to persons with HIV/AIDS on older parents in Thailand. Retrieved April, 20, 2008 from http://www.psc.isr.umich.edu/pubs/pdf/rr02-527.pdf

Knodel, J., Saengtienchai, C., Im-em, W. & VanLandingham, M. (2000) The impact of Thailand's epidemic on older persons: Quantitative evidence from a survey of key informants. Retrieved April, 20, 2008 from http://www.psc.isr.umich.edu/pubs/pdf/rr00-448.pdf

Levin, O. (2006) *An exploration into the use of art therapy as a coping mechanism for guardians caring for children orphaned by AIDS in Vosloorus, Johannesburg*. Johannesburg: University of Witwatersrand

Mango, T. (2004) *An evaluation of psychological services for individuals living with HIV/AIDS and their communities in Lusikisiki in the Eastern Cape Province*. Johannesburg: University of Witwatersrand

Marais, H. (2005) Buckling: The impact of AIDS in South Africa. Centre for the study of AIDS, University of Pretoria. Retrieved 15 March 2007 from http://www.csa.org.za

Mathebula, S. P. (2006) *Challenges of home-based caregivers of HIV/AIDS patients at the Muslim AIDS Programme*. Johannesburg: University of Witwatersrand

McKenzie, G. (2005) *An assessment of the psychological support given and received by Home-Based caregivers working in the North-West Province.* Johannesburg: University of Witwatersrand

Montgomery, C. L. (1993) Healing through communication: The practice of caring. London: Sage Publications

Orner, P. (2006) Psychological impacts on caregivers of people living with AIDS. *AIDS Care. Vol. 18(3).*pp 236-240. Retrieved February, 25, 2010 from informaworld.com/smpp/ftinterface~content=9743734526

Opiyo, P. A., Yamano, T. & Jayne, T. S. (2008) HIV/AIDS and home-based health care. *International journal for equity in health.* Retrieved February, 10, 2010 from http://www.equityhealthj.com/content/7/1/8

Pakenham, K. I., Dadds, M. R., & Terry, J. (1998) Carers' burden and adjustment to HIV, In R. Bor and J. Elford (eds), *The Family and HIV Today: Recent Research and Practice.* New York: Cassell

Pakenham, K. I. & McClausand, J. (2003) Investigation of the benefits of HIV/AIDS caregiving and the relations among caregiver adjustment, benefit finding, and stress and coping variables. *AIDS Care. Vol. 15(6).pp853-869.* Retrieved February, 10, 2010 from http://pdfserve.informaworld.com/217472_749440618_713611750.pdf

Pirraglia, P. A., Bishop, D., Herman, D. S., Trisvan, E., Lopez, R. A., Torgersen, C.S., Van Hof, A., Anderson, B. J., Miller, I. & Stein, M. D. (2004) Caregiver burden and depression among informal caregivers of HIV-infected individuals. *Journal of general internal medicine 2005*.vol (20) pp510-514. Retrieved February, 10, 2010 from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1490132/pdf/jgi_04106.pdf

Raina, P., O'Donell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., Russell, D., Swinton, M., King, S., Wong, M., Walter, S. D. & Wood, E. (2004) Caregiving process and caregiver burden: Conceptual models to guide research and practice. *BMC Pediatrics*. BioMed Central. Retrieved February, 10, 2010 from http://www.biomedcentral.com/1471-2431/4/1

Sarantakos, S. (2000). Social Research (2nd Ed). China: Palgrave.

Sibuye, V. B. (2008) *The challenges faced by caregivers working at hospice (CARE Centre). Johannesburg*: University of Witwatersrand

Simpson, S. (2006) *A technical report exploring whether caregivers of people living with HIV/AIDS receive sufficient psycho-social support: A South African descriptive study at community care project*. Cape Town: University of Stellenbosch. Retrieved September, 17, 2008 from http://www.csa.org.za

Skinner, D. & Mfecane, S. (2004) Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa. *Journal of Social aspects of HIV/AIDS* Vol. 1 (3)

Terre Blanche, M., Durrheim, K and Kelly, K. (2006) First Steps in Qualitative Data Analysis. In M. Terre Blanche, K. Durrheim and D. Painter (eds). *Research in Practice: Applied Methods for the Social Sciences* (2nd Ed) South Africa: UCT Press.

UNAIDS (2000) Caring for Carers: Managing Stress in those who care for people with HIV and AIDS. Geneva: UNAIDS.

UNAIDS (2008) Caring in the context of HIV/AIDS. Geneva: UNAIDS. Retrieved February, 25, 2010 from www.un.org/.../EGM-ESOR-2008-BP.42%20%UNAIDS_Expert%20panel_paper=%20Final.pdf

UNAIDS (2008) Preventing carer burnout: Inter-Mission Care and Rehabilitation Society (IMCARES). Geneva: UNAIDS. Retrieved February, 25, 2010 from www.un.org/.../EGM-ESOR-2008-BP.42%20%UNAIDS_Expert%20panel_paper=%20Final.pdf

Webb-Robins, L. M. & Wilson, Z. (2008) Analysis of HIV caregivers in South Africa: A South African depression and anxiety group. *Journal of human behaviour in the social environment* Vol. 17 (3-4). The Haworth press, Inc. Retrieved November, 5, 2010 from http:// o-web. ebscohost. com. innopac. wits.ac.za\ehost\pdfviewer?hid=109&sid=d6370258-e7f9-433f-b93d-274b3128fafc%40sessionmgr112&vid=4

Whiteside, A & Sunter, C. (2000) The economic, developmental and social impact of AIDS. In *AIDS: The challenge for South Africa.* (pp 82-97). New York, Palgrave Macmillan.

Wight, R.G., Le Blanc, A. J. and Aneshensel, C. S. (1998) Support Service Use by Persons with AIDS and their Caregivers, In R. Bor and J. Elford (eds), *The Family and HIV Today: Recent Research and Practice.* New York: Cassell.