

THE PSYCHOSOCIAL IMPACT OF CARE-GIVING ON THE FAMILY CARE-GIVERS OF CHRONICALLY ILL AIDS/HIV PATIENTS IN HOME BASED CARE

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

Johannesburg 2010

DECLARATION

I, Natsayi Geraldine Matimba declare that this research report is my own work. It is being submitted for the degree of Masters in Family Medicine in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.

Signed.....

Dated this.....day of....., 2010

In memory of my baby girl

Nenyasha Mujuru

Born and died

09-01-2006

ABSTRACT

The family care-giver has a pivotal role to play in the management of the chronically ill HIV/AIDS patient. The well being of the care giver is therefore crucial since impairment of their physical or mental health could impact negatively on the management of the HIV patients.

Aim

The purpose of this qualitative study was to find out the psychosocial impact of care-giving on the family care-giver of the chronically ill HIV/AIDS patient in home based care.

Methodology

In-depth, tape recorded, unstructured interviews were conducted on eleven care-givers recruited at an adult HIV clinic at United Bulawayo Hospitals, Bulawayo, Zimbabwe. Relevant demographic data was collected from each participant. The interviews were then transcribed before analysis of the data was done.

Results

The care-givers biggest challenge was meeting care costs such as food, transport and medical expenses. Certain conditions relating to the care-recipients' health and family issues such as abandonment of the ill patient and orphans added to the burden of care. Carers also had health and physical factors that impacted on their psychosocial well being. All these issues resulted in a spectrum of emotions such as helplessness, sadness, anxiety and anger but despite this the carers still reported on positive aspects of their care-giving role.

Conclusion

Care-giving impacted negatively on the care-givers' psychosocial well being but there were also positive aspects to the role.

ACKNOWLEDGEMENTS

I am very grateful to Dr Anne Wright, my supervisor, for her support and encouragement from the conception to the completion of this study. I would also like to extend my heartfelt gratitude to Sister Gumbo and all the staff at Opportunistic Infection Clinic, United Bulawayo Hospitals for their assistance with the recruitment of the participants. Many thanks to all the participants without whose participation this study would not have been possible. Lastly, I am immensely grateful to my husband Tich Mujuru for his support financially, emotionally and above all for being so patient with me while I struggled to work on this research.

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CHAPTER 1

1 INTRODUCTION

1.1 Background

Zimbabwe, like most countries in southern Africa has been significantly affected by the HIV/AIDS epidemic. The first case of AIDS was officially reported in Zimbabwe in 1985 and since then the epidemic has had devastating and far reaching effects on the lives of Zimbabweans.

Figures from UNAIDS 2008 update¹ provide an understanding of how the epidemic has had a dramatic effect on this troubled country since that first case was reported. This report estimates that the adult HIV (15-49) prevalence in 1990 was just under 15% and rose sharply to 29% around 1998. The prevalence has however been on the decline since then and was stated to be to 15.3% in 2007. This reduction in prevalence is believed to be a result of several factors including high mortality rates, migration to other countries and a decrease in new HIV cases because of behaviour change². In terms of actual numbers the update estimates that in 1990 close to 700 000 people were living with HIV compared to 1 900 000 in 2001 when the peak number of people living with HIV was reached. Annual number of deaths rose steadily from around 23 000 in 1990 to 170 000 in 2004 and has also been going down since then but the worsening economic woes and resultant poverty could reverse this downward trend of AIDS deaths because of poor nutrition and the virtually collapsed health system^{2, 3}.

The most dramatic figure that shows how AIDS has affected Zimbabwe is the fact that the life expectancy at birth for both sexes has dropped from 65 in 1990 to 43 in 2006 according to a December 2008 WHO report³. However a report in The Independent in November 2006 quoted an unnamed WHO officials who spoke off the record as saying that the life expectancy was as low as 34, the lowest in the world at that time⁴. A similar figure is also quoted in a USAID September 2008 report⁵ which stated the life expectancy to be 37. If these figures are indeed accurate the overall life expectancy would therefore be close to half of what it was almost twenty years ago which is indeed very alarming.

The rapid increase in the number of orphans in Zimbabwe also highlights how the epidemic has impacted on this nation. UNICEF estimates that there were 345 000 AIDS orphans (0-17years) in 1988 and the number rose to 1 300 000 in 2006⁵. What is astounding is the fact that this latter figure represents about a quarter to one fifth of the total number of children in the country^{5, 6}. In order to fully appreciate this burden of AIDS orphans it is estimated that four out of every five orphans have lost one or both parents to HIV/AIDS⁵. A study to quantify and describe orphan incidence in the eastern province of Manicaland in Zimbabwe which was done between 1998 and 2003 also supports this figure since it revealed that 82% of the children had been orphaned to HIV-related deaths⁷. The investigators concluded that these huge numbers of orphans have placed tremendous pressure on the extended family, the size of which has been depleted by the large number of AIDS deaths.

Although the adult prevalence of HIV infection in Zimbabwe has almost halved from its peak of 29% in the late nineties to 15.3% in 2007 as mentioned above there was still a staggering 1 320 739 adults and children living with HIV/AIDS by the end of 2007 as reported in the United Nations General Assembly (UNGASS) Report on HIV/AIDS⁸. This high number of people living with HIV/AIDS is further compounded by the fact that the number of people receiving antiretroviral therapy (ART) is still quite low compared to the number of people needing the therapy. The number of people on ART has been on the increase from a mere 8 000 in 2004 to 98 000 in 2007¹ thanks largely to the Ministry of Health and Child Welfare's initiative aptly named the Plan for Nationwide Provision of ART (2005-2007), the goal of which was to reduce HIV/AIDS related mortality and morbidity⁸. Despite this increase in the number of people receiving treatment, the ART coverage was still very low at 19% by the end of 2007 according to UNAIDS/WHO¹ although the UNGASS has a much higher percentage coverage of 38% for the same period⁸. Whatever the correct coverage percentage is this has most likely decreased due to the worsening economic situation prevailing in the country which necessitated the Plan for Nationwide Provision of ART to revise its initial higher targets due to many challenges such as dwindling health personnel, severe foreign currency shortages to procure the drugs or raw materials for local production and a higher demand for ART⁸. Both the large population of people living with HIV/AIDS and the inadequate provision of ART

contribute to a high AIDS death rate. This has remained high despite the declining prevalence and is reported to have been 140 000 in 2007 alone, not that much lower from the 150 000 recorded in 2001 considering that the prevalence has almost halved¹. With such alarmingly figures it is not surprising that the health care sector is facing serious challenges in providing care to those afflicted by HIV/AIDS who require long term health care as a result of the natural progression of the disease particularly given the inadequate access to ART to reverse the deterioration in the immune system.

This outline on the status of the HIV/AIDS epidemic in Zimbabwe is incomplete without discussing the politico-socio-economic situation facing the country because obviously it impacts on the epidemic on a national, community and personal level. The government of Zimbabwe has responded positively to the AIDS epidemic through various initiatives such as the setting up of National AIDS Co-ordination Programme in 1987 which later gave way to the National AIDS Council (NAC) in 1999 whose task was to coordinate the government's response to HIV and AIDS through a multi-sectoral approach^{2, 8}. Zimbabwe was hailed for being the first country in the world to introduce a 3% AIDS levy on taxable income from all sectors to finance NAC in its mandate to tackle the epidemic⁵. There was also the implementation of national short and medium term AIDS plans in the eighties and nineties. The Zimbabwean government was also involved in ratifying several international commitments to improve the response to the epidemic such as "Millennium Development Goals, Goal 6 sought to halt and reverse the spread of the HIV and AIDS epidemic by 2015" (2000), "The Glenagles G8 Universal Access Targets" (2005) and "The African Union's Abuja Call for Accelerated Action" (2006) amongst others⁸.

The positive effects of these commitments have, however, been reversed by the economic meltdown that has hit the country. Economic experts believe this has resulted from bad governance^{9, 10}. The economic deterioration started after the land invasions of 2000 which seem to have been precipitated by a constitutional referendum that the government had unexpectedly lost¹⁰. The agricultural sector, once a backbone of the economy, virtually collapsed overnight with marked reduction of food production. There was worldwide condemnation of the invasions with withdrawal of donor aid which the government cites as the cause of the economic woes but analysts dispute this as the reason for the state the country is currently facing¹⁰. The government is instead blamed for running huge fiscal

deficits and their response to that has been to print money which has caused hyperinflation^{9,10}. In turn, their reaction to the hyperinflation has been to introduce price controls which has had the result of creating shortages of commodities including fuel which has further worsened the availability of food^{9, 10}. The government's rhetoric against the West and other policies as well as the general disregard of the rule of law have scared away investors in other sectors which has exacerbated the situation^{9,10}. All this has resulted in Zimbabwe becoming the first country in the 21st century to hyperinflate although official figures are not available¹¹. The estimated monthly inflationary rates have soared from 77% in Jan 2007 to an astounding 79 600 000 000% in November 2008¹¹! Poverty levels have therefore risen from 35% of the population living below the poverty line in 1996 to an estimated 80% by 2003 and this figure has certainly increased since then^{10,12}. According to media reports in January 2009 the UN's Office for the Coordination of Humanitarian Affairs (OCHA) approximated that the unemployment rate by end of 2008 was at a staggering 94% compared to 39% in 2003¹³. There is a deterioration of the nutritional status because of this increase in poverty with 30 to 40% of the children being stunted³.

This economic meltdown has resulted in the near total collapse of all service delivery such as health, education, water and electricity. Delivery of healthcare has also been affected by the forced internal displacement of the population due to the land invasions of 2000 and 2001 whereby 800 000 farm workers and their families were displaced¹⁰ and Operation Murambatsvina in May and June 2005 which alone is believed to have displaced 700 000 people, 79 500 of whom were living with HIV whose access of ART and monitoring were obviously disrupted^{2,10}. People have also been displaced both internally and externally by pre and post election violence over the years. There has also been a massive exodus of Zimbabweans to neighbouring countries for political and economic reasons with around three million people believed to have migrated to South Africa alone. This migration has further contributed to worsening of the poor service delivery. Healthcare personnel like other professionals have also left the country in large numbers in search of greener pastures which has contributed to the decline in healthcare delivery resulting in severe staff shortages with 56%, 32%, and 92% respectively of doctors, nurses and pharmacist positions vacant³. They have been forced to do so because of low salaries which are far from adequate for the high cost of living the country is grappling with⁸. Shortage of

healthcare staff like all other sectors has also been compounded by high mortality due to the AIDS epidemic itself². The recent cholera outbreak which started in August 2008 is believed to have been caused by all these factors of poor service delivery in terms of healthcare and water supply, overcrowding due to the displacement and poverty³.

Given the state of the healthcare system in Zimbabwe it is not surprising therefore that the care of the chronically ill has become largely the responsibility of the family. Even in other developing countries that do not have the dire economic challenges facing Zimbabwe now, home based care is an integral and essential part of the management of these patients. This is because the human and economic resources at hospitals cannot cope with protracted hospital admissions as well as the sheer numbers of admissions required because of the chronicity and disabling nature of AIDS especially in communities with high prevalence of HIV such is the case in Southern and Eastern Africa. It was projected that a five point increase in prevalence will increase demand for health care by 25% and that hospital bed occupancy due to AIDS in urban areas will rise to between 50% and 80% in Ivory Coast, Burundi, Zambia and Zimbabwe because of their high prevalence rates¹⁴. A 2000 UNAIDS source revealed that about two thirds of the hospital admissions in Zimbabwe was required by AIDS patients¹⁵. As a result of this demand for medical care the Zimbabwe government in conjunction with non-government organisations, civil society and church organisations have been promoting home based care and have been involved in training home based care community workers who assist the primary caregivers, the family members of those affected, to take care of their loved ones at home¹⁶. However, the functions of these organised home based care projects have been disrupted by reduced funding from international donors with only US\$4 and US\$17 estimated to have been received per person living with HIV per year in 2006 and 2007 respectively compared to the average of US\$74 per person in other countries in the southern African region and USD\$184 in Zambia^{6,16}.

The scaling down of the services of the community home based care projects therefore means the family carers no longer enjoy the assistance and support of the trained community volunteers in areas such as health care, nutrition, clean water and sanitation, food security, counselling and income generating projects and provision of consumables such as gloves, napkins and bandages¹⁶. These family care-givers play a pivotal role in the

management of these patients in terms of emotional support, assistance with activities of daily living and medical care. They also play a big role in the interaction between the patients and the formal health care sector. It is important therefore that their well being is maintained since impairment of their physical or mental health could impact negatively on the management of the HIV/AIDS patients.

I chose to do this study because I have encounters in my practice with care-givers of AIDS patients and some of them have expressed feelings of despair about the care-giving process. I have also noticed some spouses especially wives, tend to exhibit impatience or anger towards their ailing partners. I have always wondered if this is a result of the stress of care-giving or anger emanating from blaming the ailing partner for bringing the disease upon the family. Some of my patients are also in the care of the elderly relatives or distant relatives which could have challenging implications. I therefore felt compelled to find out the psychosocial burden of care-giving on the care-givers in my community.

1.2 Aim

To study the impact of care-giving on the psychosocial health of family care givers of HIV/AIDS patients in home based care who attend HIV clinics which are known as OI (Opportunistic Infection) clinics at United Bulawayo Hospitals (UBH) in Bulawayo, Zimbabwe.

1.3 Objectives

To describe the demographic profile of family caregivers of HIV/AIDS patients in home based care.

To explore the psychosocial impact of care-giving on the family care-giver of the chronically ill HIV/AIDS patient in home based care.

To explore the care-givers' perspectives on the effect of care-giving on their psychosocial health.

CHAPTER 2

2 LITERATURE REVIEW

The impact of care-giving on the well being of the care-giver of HIV/AIDS patients has been studied in different communities across the world^{17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27}. The overall results reveal that these care-givers do suffer from significant psychosocial problems. The problems encountered included depression, anxiety, loneliness, anger, fear and stigmatization and economic difficulties. The extent of care-giving in these studies included assistance with activities of daily living, management of the disease and medications, emotional and financial support. In this era of the HIV/AIDS epidemic, the effect of care-giving on the carers of HIV/AIDS patients has become an important area of research because of the chronic and debilitating nature of the disease which necessitates care of the sufferers to be provided mainly at home.

The various studies on HIV/AIDS caregivers mentioned above include six studies from different countries in Africa^{17, 20, 21, 22, 23, 25}. In the first study the experiences of older women and young girls caring for family members with HIV/AIDS and other chronic terminal diseases were explored in a study on home based care in Botswana¹⁷. Both groups of women reported feelings of depression, loneliness and isolation but in addition to that the older women also complained of exhaustion because they often had more than one family member to give care to. They admitted to feeling overwhelmed by the load of the work they had to do such as taking care of the ill person with incontinence, vomiting, confusion, skin lesions and constant pain as well as the general household chores of fetching water and firewood, cooking and cleaning. As a result of these burdens they tended to neglect their own health and nutrition. The researchers found that there was a stigma attached to home based care because of its association with the HIV/AIDS which exacerbated the isolation that the care-givers felt because of the sheer burden of care-giving that did not allow the care-givers to engage in social activities outside the home. Older care-givers were also separated from their usual support systems when they sometimes had to go and tend to their ill children who lived away from the home village because of employment in urban areas but in other instances the ill relatives moved back

to the rural home where the older women were residing. Another source of stress was loss of family income as HIV/AIDS affects the young and financially productive members of the family and this further compounded the emotional distress experienced by these women. Challenges unique to the younger women included sexual exploitation and abuse by older men as they often felt desperate to ameliorate the family poverty brought on by the disease and they also suffered disruption of their education.

A study done exclusively on elderly caregivers of 50 years and above that was conducted in rural Uganda²³ showed similar results to the Botswana study. The respondents reported that caring for their ill relatives impacted negatively on their family income in three ways. Firstly from loss of financial support from the ill relatives who are no longer able to work, secondly from less resources since the caregivers themselves can no longer work on their own income generating activities and finally from loss of savings and personal belongings as these are often sold in order to pay for the treatment of the ill and for food for the family. They also expressed feelings of depression, worrying and hopelessness. They worried not only about the situation they found themselves in but also about their future and that of the ill ones and their children who were also often in their care. Worry also stemmed from fear of contracting the disease as they often lacked protective gloves. They felt their efforts were futile and found the burden of supporting their ill relatives emotionally draining especially if they were in denial about the illness or were struggling emotionally. Just like the elderly caregivers in Botswana they also felt isolated socially because of the demands of the care-giving process. However, a few female respondents felt a strengthening of some of their friendships as they received comfort from visits of their friends. Physically they suffered from inadequate nutrition due to insufficient resources and poor appetite as a result of worrying and the female caregivers also reported experiencing various body pains, weight loss, lack of sleep and fatigue much more than the men.

The majority of AIDS care-givers studied in rural Tanzania were female over fifty years old²⁵; only four of the sixty respondents were male so it is not surprising that their experiences are almost the same as those outlined in the previous two studies. The researcher of that study grouped those experiences into three main categories namely poor financial resources, lack of physical help with the care-giving and loneliness which was

partly due to stigmatisation. A very interesting study was conducted in the Caprivi Region of Namibia which studied the impacts of HIV/AIDS on both patient and carer well being by utilising solicited diaries. The researcher concluded that the threat to household food security and family income as a result of the caring process was a major issue especially if the ill person had been the main breadwinner for the family or if the ill person was very dependent and needed more assistance for protracted periods. The inability to provide for the household was a cause for great emotional strain amongst other stressors such the failure of improvement of the ill person, fear of contracting HIV in the course of performing the caring duties, isolation and decreasing support from other relatives especially with extended periods providing care. This diminishing support was found to be due in part to the stigma attached to being chronically ill and partly due to the inability of the carer and the care recipient to give reciprocal support to others because of the load of care-giving and the burden of the disease. Initial diary entries had revealed that that the carers were committed to giving the best care possible under the circumstances but over time the burden of caring resulted in bad feelings and tensions not only between the care-giver and the care-recipient but also within the household. Mood changes between the two were to blame for causing the tensions and these were brought on by the fluctuating health condition of the ill person with periods of ill health associated with unhappiness, frustration and anger and optimism and improved mental well being during episodes of improved health. The researcher observed that these emotional upheavals can result in the carer becoming insensitive to the needs of the ill person and withdrawing from them which will impact negatively on his or her care.

In contrast nine out of the fifteen care-givers of patients with symptoms of AIDS studied in a very poor rural community in Malawi²⁰ responded to the question of what problems they experienced by stating that they were no problems. On further probing though it was apparent that there they had emotional, physical and financial strains. The emotional worries arose from failure to provide special foods for the patient and their failure to improve. However, the care-giving did not seem to affect their family income significantly because few were receiving money from the ill relative before the illness or earning an income before they became involved in care-giving, they also only had a few belongings to sell. As the researcher put it “they spent little because they had little” which he said was not the case with better off urban dwellers who had more money to spend on a wider range

of choices such as school fees, hospitalisation and anti-retroviral drugs. What is striking with this study is that the care-givers were very dedicated and caring in their duties and did not seem to report on the frustrations revealed by the other studies discussed above and that they also reported on receiving some financial, physical and moral support from their other relatives and the community. This maybe partly because most of them had been giving care for less than four months and due to the unavailability of effective medical interventions the patients tended to die before care-giver burnout had set in. It is also interesting that there was no evidence of stigmatisation towards either the care-giver or the care-recipient in this community.

In order to obtain the data required all the studies from sub-Saharan Africa discussed above employed qualitative methodology in the form of focus group discussions, in depth interviews or as in the case of one study, solicited diaries. What they also have in common is that they were done primarily in rural areas with only two out of the five studies combining participants from both rural and urban communities. One study done in Kinshasa, the capital of the Democratic Republic of Congo on care burden and self-reported health status of informal women caregivers of HIV/AIDS patients was more quantitative in its approach by utilising a semi-structured questionnaire with 38 items²². Another contrast between this study and the others is that all eighty women were by sheer coincidence spouses of the patients as opposed to being different relationships as in the other studies. Interestingly, all the eighty women reported to be HIV positive. Selection criteria for this study excluded women older than 50 years because the researchers wanted to find out the effect of care-giving on women with children in the home so they were all younger than the study population of the other studies. These women were also enrolled with a home based care programme so they all received at least one visit from a trained home based worker a month.

Despite their younger age, better family incomes than the rural populations, urban domicile with presumably better health facilities and the benefit of some support from the home based programme 94% of these Kinshasa care-givers said they found care-giving difficult and 98% said they frequently experienced lack of food and irregular drug supply. The limited food supply was due to both shortage of money and inconsistent food availability. 89% of them admitted to care-giving being very stressful, 10% found it fairly

stressful while only one participant did not find it stressful. Stigmatisation and ostracism from relatives, friends and neighbours and even the husband's employers was perceived by 90% of the women while all of them had limited time for themselves and their children and 99% said their social interactions had been significantly reduced by the care-giving process. Stress was exacerbated by mental distress such as agitation, depression and aggression of their patients with 77% of them reporting on those episodes. Unhappiness was very high amongst the women with 48% feeling that they were so unhappy that life was no longer worthwhile and a further 40% feeling that they had little interest in life. 94% had physical ailments and symptoms such as headache, abdominal pain, anorexia and lethargy with a mean self-reported health status (SRHS) score of 9,1. An SRHS score of 13 is the highest score and it denotes poorest health. Those with higher SRHS scores reported that they felt ostracised and unsupported in their care-giving role. The high SRHS did not appear to be due to their positive HIV status because none of them had signs of AIDS, they were all capable of doing the physical work demanded by the caring role and their physical symptoms had started after they had assumed the care-giving role.

Literature review of the research done in the developed countries on care-giving of HIV/AIDS sufferers largely involves low-income, minority ethnic groups and gay communities^{18, 19, 24, 26, 27, 28}. The reasons being that these are the communities that are mainly affected by the disease due to higher prevalence of unsafe intravenous drug abuse and higher infection rates through both homosexual and heterosexual spread. This is in contrast to the prevalence of HIV/AIDS in sub-Saharan Africa where the disease has no strong predilection to particular socio-economic and ethnic groups and where heterosexual spread is predominant. Unlike in Africa where most of the AIDS care-giving is done by females, a considerable number of care-givers in the developed countries are men because of the large communities of gay men found there^{26, 28}. Another difference is that there are obviously better health care facilities as well more supportive programmes in the developed countries than in the developing countries. After exploring how care-givers in the developing world are faring it is therefore imperative to also explore how the care-givers in developed countries such are coping given these differences.

A quantitative study was done to explore the health problems of low income female care-givers of heterosexual and homosexual men and women with HIV/AIDS in Southern

California using various structured instruments¹⁸. Mental health problems were mainly due to depression and this was found to be related to poor functional status, number of physical symptoms, and memory and behaviour problems of the patient. Anger and loneliness were also common in the care-givers. They felt lonely despite being surrounded by family and friends and like the care-givers in the African studies they did not have time to attend to social activities because of the demands of care-giving. The anger they felt was directed at themselves for taking on the care-giving responsibility, other family members for not being supportive and the patient for their irresponsible behaviour which they felt was to blame for them contracting the disease. Many of the participants were grateful for the opportunity to share their care-giving experiences with the interviewers, an encounter they said they found cathartic especially since none of them surprisingly had formal support from any community programmes. 59% rated their physical health as being poor to very poor but interestingly their scores for physical health had no relation to the degree of physical assistance they had to provide instead poor physical health scores were definitely related to longer period in care-giving.

A study focusing exclusively on gay men caring for their partners was conducted in Australia²⁸. A common feature in this group of carers was the fact that they felt no anger towards the person they were caring for over contracting the disease because they regarded the situation as “it could have been me”. As a result of this attitude they placed less emphasis on their own care-giving challenges and more on the partner’s needs. They continued to engage in safe sexual activities with their ill partners if their condition permitted it of course. This lack of reservation towards care-giving of a fellow gay man, the authors felt maybe because they believed that they would also eventually succumb to the illness. All twelve participants involved in the study admitted to isolation and stigmatisation firstly from being homosexual and secondly from dealing with AIDS because of its sexual mode of transmission and terminal nature. This perceived stigma often prevented the carer from seeking assistance from health care facilities and home based programmes or from friends and relatives. Other problems included those faced by heterosexual care-givers such as partner’s denial of the illness, managing the medical treatment and coping with difficult conditions such as dementia. Their coping strategies included use of humour and investing in the quality of their remaining time together in their attempt to deal with the anticipatory grief they experienced in the final stages of the

disease. Planning for their partner's funeral and being able to carry out their final wishes offered some comfort especially given the limited civil liberties in gay relationships.

The twenty caregivers of AIDS sufferers studied in south-eastern Brazil²⁴ revealed that their main issues were inadequate information on the transmissibility of the virus as well as associated conditions such as tuberculosis. This caused undue fear of acquiring HIV infection. They also found following instructions regarding the medical treatments challenging because of their low level of schooling. Just like the care-givers in Africa they had insufficient funds to buy protective gloves, nappies, transport to and from the hospital and for meeting the funeral costs in the inevitable event of the death of their ill relative. In similarity to their counterparts in both the developed and developing world, they felt unsupported in their care-giving duties and also emotionally which resulted in work overload and fatigue. They also had to deal with the stigma associated with AIDS as well as their own prejudices about the disease. They admitted to feeling revulsion towards the ill person in cases where the diagnosis exposed infidelity, divergent life style and sexual practices. This revulsion, in the case of mothers was replaced with resignation but wives remained repulsed and angry until the death of the ill husband even though they continued to provide them with the required care. These care-givers worried about the death of their relative specifically about how and where they were going to die.

This extent of care-giving is associated with mental and physical problems in the care of other chronic and incapacitating diseases such as dementia and advanced cancer and has been well documented and researched over the years^{29, 30, 31}. A study comparing the emotional distress of female care-givers of people with AIDS, age-related dementias (ARD) and advanced cancer (CA)³² revealed that all three groups of care-givers expressed comparable levels of depressive mood although the individual depressive mood items differed. Care-givers of the AIDS patients experienced loneliness, crying and feeling that life had been a failure whereas care-givers of CA and ARD sufferers were more positive and did not feel their lives were a failure. Both CA and AIDS care-givers felt sad and "like they couldn't go on". When it came to anxiety, the CA care-givers felt most anxious whereas the ARD ones were the least anxious. The former were also found to have more anger symptoms namely tendency to bad temper and being critical of others compared to the other two groups. Most of the care-givers of all the three groups had sleep problems

although the sleep patterns differed. Interestingly, care-givers of people with ARD seemed to have less distressing emotions despite the longer duration of care-giving and the older age of the care-givers. Another comparative study exploring the physical and psychological health of AIDS and cancer care-givers also revealed that both carers experienced almost the same levels of depression, grief, symptoms of stress and health³³. The difference was that the cancer carers had better social support systems than the AIDS carers although the latter found care-giving more rewarding.

There are factors that may worsen the magnitude of psychosocial well being of care-givers in Zimbabwe compared to the developed world. Lack of social support for the care-givers due to the loss of other family members and friends as a result of high number of AIDS deaths, inadequate formal support services, the young age of the care-receiver, late diagnosis and severe debilitation of the care-receiver because of limited access to anti-retrovirals and general health care are all factors that can exacerbate the distress that is usually associated with care-giving.

Cultural factors such the extended family system that exists in the African setting may ameliorate the psychosocial burden as opposed to the nuclear family system that is prevalent in the developed world. Care-giving has also been associated with a sense of fulfilment³⁴, a phenomenon which could be prevalent in the proposed study population because it is not uncommon for the care-giver of some of the adult care-receivers in Zimbabwe to be the mothers of these patients. The inherent nurturing quality of this relationship may therefore impact positively on the caring process for some of these care-givers. It would also be interesting to explore how spousal care-givers are coping because of the heterosexual spread of the virus and the potential for feelings of blame and guilt that could exist between the care-giver and care-receiver dyad for bringing the disease into the family.

CHAPTER 3

3 METHODOLOGY

3.1 Design of the study

This is a descriptive study using qualitative methodology. Qualitative methods have been chosen for this research in order to explore the experience of care-giving and its impact on the psychosocial well being in this understudied population. This is because “human emotions are difficult to quantify; qualitative research seems to be a more effective method than quantitative research for investigating these emotional responses”³⁵. There were no published articles on AIDS caregivers of studies done in Zimbabwe so a qualitative approach was the more appropriate method to find out in general the experience of these caregivers so that hypotheses for probable future research can be discovered³⁶.

3.2 Site study

The study was conducted at the Opportunistic Infection (OI) Clinic at United Bulawayo Hospitals (UBH) in Bulawayo, Zimbabwe. The clinic is wholly dedicated to management of HIV/AIDS patients. The clinics are run by medical doctors with support from the other disciplines such as adherence counsellors, nurses, pharmacists. The adult clinics are run on Tuesday, Thursday and Friday mornings. The service is provided virtually for free except for a nominal amount and is funded by the Ministry of Health/Child Welfare. Patients are referred to the clinic from the hospital wards, local government clinics, voluntary testing centre as well as private doctors working in and around Bulawayo. Bulawayo is the second largest city in Zimbabwe, a country in southern Africa which shares borders with South Africa, Botswana, Zambia and Mozambique.

3.3 Study population

Adult care-givers of any type of relation to the home based chronically ill adult HIV-positive patients who attend the OI clinic at UBH.

3.4 Sampling

3.4.1 Recruitment

Participants were recruited directly from the OI clinic. At the end of the consultation of the patient who was accompanied by a care-giver, the doctor or nurse informed the care-giver of the study and then directed them to the researcher. The researcher also identified chronically ill patients who were accompanied by a caregiver in the waiting rooms. Accompaniment by a care-giver was therefore the indicator that that particular patient required care and hence the sampling was purposive because the recruitment of the participants was done from a group of individuals who bore the characteristic the researcher was interested in³⁷. The researcher would then explain the nature of the study to the care-giver and provide an information sheet written in their preferred language for them to read. The information sheet outlined the reasons for the study, the participation required and consent issues. The prospective participants were also screened for eligibility to participate at this point and those who did not fit the criteria were informed. Since the normal process at the clinic is a lengthy one ordinarily and the interview itself was scheduled to take at least an hour, arrangements were made with those who were willing to participate to meet the researcher at an appointed time and place. The prospective participants could choose to have the interview either at the researcher's office in town or at their own home. Those who opted to meet in town were given money to travel to the venue at that first contact at the clinic.

3.4.2 Inclusion criteria

- Care-givers and care-receivers should be adults (over 18 years) because of issues of consent.
- Care giving done in community since this is the basis of the study.
- Assistance with ADL (activities of daily living) and not emotional or financial support only.
- Length of care-giving should be for period of 2 weeks or more.
- Currently residing in Bulawayo in order to facilitate the interview.
- English or Shona speaking since the researcher cannot speak Ndebele which the predominant vernacular language around Bulawayo.

3.4.3 Exclusion criteria

- Pregnant care-givers since response to care-giving could be affected by emotional and physical changes
- Care-givers who are health professionals because this may introduce a bias

3.4.4 Sample size

A total of fourteen participants were recruited from the clinic but only eleven were interviewed. Two prospective participants did not come for the interview because the patients died before the scheduled interview and the third one decided against participating. The sample size was determined by reaching the saturation point, the point at which the researcher finds that there is no longer any new information emerging from the interviews³⁸. This required the researcher to continually analyse the collected material in order to be in a position make that evaluation.

3.5 *Measuring tools and data collection*

The data collection took place either at the care-giver's home or at the researcher's dedicated office as arranged earlier at the OI clinic. After the initial greetings the procedure of the interview was outlined and this was then followed by informed consent being obtained from the participant in writing. Separate consent was also obtained for tape recording the interview. The liberty to withdraw from the interview was clearly and without fail explained to each participant at this juncture. The researcher then gave assurance in writing to the participant of the confidential handling of all the information that will be shared. The following demographic information was then collected by filling in a simple questionnaire:

- Age of care-giver
- Age of the care-receiver
- Sex of care-giver
- Sex of the care- receiver
- Employment status of the care-giver -: unemployed, self employed, formal employment
- Relationship of care-giver to care-receiver
- Sero-status of the care-giver -: positive, negative, unknown, withheld
- Duration of care-giving

- Patient's Karnofsky score³⁹

Although this is a qualitative study it is important to know the demographic factors of the people providing care in the community being studied since some of the variables may influence the care-givers' coping skills. The care-receivers' level of incapacity determines the degree of care-giving required and this was measured by the Karnofsky score as follows:

- 100-: Normal; No complaints nor evidence of disease. Able to work.
- 90-: Able to carry on normal activity; Minor symptoms. Able to work.
- 80-: Normal activities with effort; some symptoms. Able to work.
- 70 -:Cares for self; unable to carry out normal activity. Independent; not able to work.
- 60-: Disabled; dependent. Requires occasional assistance; cares for most needs.
- 50-: Moderately disabled; dependent. Requires considerable assistance and frequent care.
- 40-: Severely disabled; dependent. Requires special care and assistance.
- 30-: Severely disabled. Hospitalised, death not imminent.
- 20-: Very sick. Active supportive treatment needed.
- 10-: Moribund. Fatal processes are rapidly progressing.

(Adapted from Karnofsky, Abelmann, Craver & Burchenal, 1948)

After completing the demographic questionnaire, the participant was then invited to share his experience of the care-giving process by the use of an in-depth or unstructured one to one interview which allows him to tell his story freely and in his own words and from their own viewpoint^{40, 36}. The invitation to share this story was extend to the participant by the researcher by asking this main question:

“How are you finding the experience of taking care of your ill relative?”

This open ended question was be used to obtain the required information concerning the participants' experience of care-giving³⁶. Additional questions were used only for clarification of specific points that would have been raised. The interviewer employed the techniques of clarification, reflection and summarization in order to ascertain that the

researcher had understood the participant's full perspective and to encourage the flow of conversation between the interviewer and interviewee⁴¹. The interview was recorded on audio-tape and some important points were jotted down on the field notes in order to highlight issues such as non-verbal communication. The interviews were conducted exclusively by the researcher either in Shona or a combination of English and Shona and lasted an average of an hour. The interview was then transcribed by the researcher on the same day to allow for better recall of the interview and other events surrounding it⁴⁰.

3.6 Pilot Study

A pilot study involving 3 participants from the same OI clinic that was used for the main study was conducted to assess the time required to complete the interview and to test the acceptability, usefulness and appropriateness of the interview question and the ability of the researcher to conduct a good interview. It was found that both the question and the researcher's interviewing skill enabled the interviewees to share their experiences and viewpoints as well as being acceptable to them. The researcher had received training in interviewing techniques as part of a Qualitative Research Workshop especially organised by the Department of Family Medicine for post-graduate students proposing to do qualitative studies for their research projects. All three interviews were included in the main study.

3.7 Sources of bias

The presence of the tape recorder may have intimidated some of the participants and therefore could have affected the flow of the conversation and the quality of the information that was shared but this did not appear to be a problem since none of the participants seemed to pay any attention to the tape recorder. The researcher was careful to place the tape recorder in an inconspicuous position.

The attitude of the interviewer may deter the participant from sharing his story freely especially if the former has strong preconceived ideas and opinions concerning the topic being studied. To avoid introducing this subjectivity of the interviewer to the interview and the interpretation thereof, the researcher's own ideas and feelings about care-giving were explored in an interview with a trainer involved in the Qualitative Research Workshop mentioned above. This was done in order to bring those ideas and feelings to

the awareness of the researcher so that she would not allow them to influence the interview as well as the analysis of the interview, a concept known as “bracketing”⁴².

Purposive sampling was used because of the limitations of the size of the pool of the study population. Only those who met the criteria who were willing to participate were interviewed, bias may have resulted because of personal interest of the participants.

The inability of the researcher to speak the predominant vernacular language of the area meant that a section of the study population may not have been included in the study, however only one person who was eligible on all the criteria was excluded because of the language barrier.

The analytic and reflective ability of the researcher and the quality of the interaction of the interviewer and interviewee are crucial factors in the data collection and analysis of qualitative research so if these factors are inadequate the research conclusions may be flawed. The qualitative research training prior to entering the research field as well as the general family medicine training and the pilot study equipped the researcher with the skill and confidence to conduct the study. For example, the interviewer was able to pick up the participants’ non-verbal cues during the interview and responded to them appropriately which facilitated the communication between them.

To enhance the credibility of the study an attempt was made by the researcher to contact the participants for verification of the summary of the interview as an accurate record of their account of their role as a care-giver⁴⁰. Unfortunately only five participants were able to do so while three of the care-recipients died before the verification could be done and the other three could not be contacted.

Ethical Considerations

Permission to conduct the study was sought from the Medical Research Council of Zimbabwe after the institutional Review Board of UBH had given their permission. The Postgraduate Committee of Witswatersrand University had initially given permission for the same study to be done in Francistown, Botswana but later the researcher requested permission from them to change the site of the study to Zimbabwe which they granted.

Ethical clearance was also obtained from the Committee for Research on Human Subjects as is the policy of Witwatersrand University. Professor Mielke of the Ethics Committee at University of Zimbabwe also gave his recommendation for the study.

All participants were given an information sheet written in their preferred language at the first point of contact at the clinic. This gave them details of the study and also explained that participation was completely voluntary and that they were free to withdraw from the study at any point. The information sheet also gave them assurance of the confidential handling of all the data disclosed to the researcher; the tapes, transcripts and any notes were to be destroyed at the end of the study and their names were not to be divulged to a third party since numbers were to be used in the data analysis instead of their names.

At the time of the interview the researcher went through the information sheet with the participant to ensure that they fully understood the nature of the study and that they were free to decline to participate or to withdraw from the study. Signed consent was then obtained from the care-giver for their participation in the research as well as separate consent for audio recording the interview. This was followed by the signing of the confidentiality clause by the researcher.

In case that any of the interviews revealed care-givers who had considerable emotional distress, the researcher was to refer them to counsellors at the OI clinic for counselling.

3.8 Data Analysis

All the interviews were audio recorded. The taped interviews were transcribed soon after the interview since it is best to “analyse the interviews while they are still fresh” in the mind of the researcher⁴⁰. The researcher did the transcribing herself and this was done word for word. The interviews were transcribed in the language they were conducted in and those sections of the interview that were in Shona were later translated into English. Any written notes that were made during the interview such as non-verbal cues were incorporated into the transcript. The transcript was presented to the interviewer where possible for verification of the accuracy of the transcribed data as mentioned earlier. Analysis of the data therefore commenced with the very first interview and was a continual process as more interviews were being conducted and transcribed. The key to the data analysis is to familiarise or ‘immerse’ one’s self in the information contained in the transcripts⁴². As the transcripts of the interviews

were analysed common themes emerged from the verbatim quotes of the interviewees and these 'codes' were highlighted by using different coloured highlighter. These codes were further analysed in order to create sub-themes which fall under the various main themes. The cut and paste method was then used to move those verbatim quotes that pertain to a particular sub-theme from each interview. By analysing the data this way the initial coding system was reviewed and adjusted several times in order to make more sound and logical interpretation of the themes and sub-themes that were emerging.

Analysis of those quotes that do not fit into the identified themes was also done.

3.9 Strengths and limitations

The obvious limitations of this study are those that are inherent to all studies done using qualitative methods in that the findings are not be easily transferable to another population because of the small sample size and non-random sampling³⁶.

Analysis of the data in qualitative research is very dependent on the researcher's skill to interpret the information gathered from the interviews but there will also be influence from the researcher's own subjective views³⁶. This is a definite limitation in this study since the researcher is a novice in qualitative methodology. Triangulation of observers, theory and method would have strengthened this research⁴³ but this was not possible logistically.

Despite the limitations mentioned above the study still managed to answer the research question "How are the family caregivers of the chronically ill HIV/AIDS patients attending OI clinic in Bulawayo experiencing this process of care-giving?" This was possible because the findings are based on the care-givers' own narratives and not on some numerical data which would not have captured the full essence of their experience³⁶.

CHAPTER FOUR

4 RESULTS

4.1 Demographics

A total of eleven care-givers were interviewed and ten of them were female. Seven of the women were aged 50 and above with the oldest being 69 and the youngest 34. Eight of the care-recipients were female and the ages of all the recipients ranged from 19 to 42. Nine of the care-givers did not know their HIV status and the remaining two were both HIV positive, not surprisingly these two were the only spousal dyads in the study. Five of the care-givers were mothers taking care of their ill children, two were sisters to the patients and the remaining two were an aunt and a grandmother-in-law.

The demographic data of the participants is as shown in table 1.

	Age	Sex	Employment	Duration in care	Karnofsky Score	Relationship to patient
Participant 1	69	F	unemployed	3 weeks	30	grandmother-in-law
Participant 2	44	F	employed	3 weeks	70	sister
Participant 3	56	F	unemployed	1 year	40	mother
Participant 4	59	F	unemployed	3 months	60	mother
Participant 5	36	M	employed	1 month	50	husband
Participant 6	34	F	unemployed	3 months	50	wife
Participant 7	58	F	employed	3 years	50	mother
Participant 8	58	F	unemployed	7 months	40	mother
Participant 9	40	F	employed	8 months	50	sister
Participant 10	64	F	unemployed	4 months	60	aunt
Participant 11	50	F	employed	8 months	40	mother

Table 1

4.2 Analysis of individual interviews

Each interview was analysed individually and the main theme of each interview was identified.

4.2.1 Participant 1

Main theme: God is the source of her strength.

This 69 year old lady was giving care to her grandson's partner whose own family had refused to look after her. She was doing her best under very difficult circumstances given that she also had three orphans in her care, two of whom were ill. She had very ill income but was uncomplaining and stoically did what she could do in terms of providing care and to provide.

"The experience of looking after my ill relative is painful but at times I am happy that I am able to look after her as there is no one else to do this except myself, her grandmother."

She strongly attributed her ability to do so to God and mentioned this several times.

"....but I bring everything before God because there is nothing else that can help me except believing in God..."

4.2.2 Participant 2

Main theme: Anxiety about whether her sister will recover or not.

Giving care to her sister was not difficult for this participant since she was able to do most of the activities of daily living on her own.

"At the moment it is not difficult because she is able to wash herself and she does not pass stool or urine in bed."

Apart from financial concerns since her ill sister's husband had lost his job and she was unable to assist financially as she was failing to raise money to travel back to her job in South Africa her biggest worry was whether her sister was going to fully recover or not.

"Nothing but it is just painful to see her ill especially knowing what she is suffering from. Wondering how her life is going to be in the future, if she is going to get better or what? I don't know." and *"But what worries me is that when she wakes up her eyes are sometimes swollen. Some day one eye will be swollen and the next day the other one will be swollen. I worry a lot about that. I wonder if it is going to get worse or improve because my young sister who came after me died. She started with swollen legs and it went up to her abdomen and she did not survive."*

4.2.3 Participant 3

Main theme: The burden of the physical work involved in care-giving.

This mother sounded frustrated about the physical work involved in giving care to her ill daughter. At the time of the interview she had been looking after her daughter for a year.

“Looking after a grown up, a grown up woman who can’t wash for herself, who can’t cook, who can’t bath herself. But in the past you would pour water in the dish she’d bath herself. But these few days of this week she can’t, she can’t even wake up. I just have to help her and lift her off the bed. It is difficult because (pause) it would be easy if when I’m going out she would just do everything for herself but she can’t so I have to think everything for her. Dress her, wash for her, iron her clothes, and cook what she wants. Sometimes I cook what she wants; I give her she says no I don’t And then she eats, afterwards she vomits; something she would have said she wants.”

She had to be probed about how she felt about seeing her daughter that ill since she was only describing the physical burden of care-giving and her frustration and helplessness is summed by her response:

“I feel very pity but there is nothing I can do. Nothing can help me to make her well again unless God makes her well. Me, there is nothing I can do.”

4.2.4 Participant 4

Main theme: Loss of income because of breadwinner’s illness.

This participant’s main issue was that she was ill herself and had been dependent financially on her now ill daughter to provide for her. She complained about this repeatedly and wept bitterly throughout the interview.

“I am suffering from diabetes, arthritis and high blood pressure. So it is difficult for me because I am also a person who needs to eat food that can build my body. But there is nowhere for me to get the food. My source for food was this daughter of mine who is now ill; she also needs help now. That is my biggest problem because ah – it worries me. Hmm, hmm it really worries me” (starts to cry) and

“I’m not lying to you but when I think of all this nearly every day I start to cry, asking God or is it Satan why my daughter is going through all this when some people don’t do so. (Cries again). Now she is going through this when I was looking to her for support. It worries me, really.”

4.2.5 Participant 5

Main theme: Intensive counselling helps him cope since he is also HIV positive.

This was the only male participant in the study and he was giving care to his ill wife. He had also been diagnosed with AIDS almost at the same time as his wife. This interview was virtually a monologue with the participant giving a long narrative of how they both came to test for HIV and the journey they had travelled since then. He shared very little about his experience of care-giving except to say this as his parting shot:

“I am going to be late for my bus so I need to go but when it comes to looking after my wife it is hard but I am coping because of all the counselling I have had as you can see.”

4.2.6 Participant 6

Main theme: Counselling helped her cope with husband’s psychotic illness.

This participant, like the one before her, also gave a narrative of her husband’s illness instead of sharing her experience of being a care-giver. Other similarities they shared are that they are the only participants in the study giving care to their spouses and they both tested positive for HIV. After she had described the psychotic illness that her husband was suffering from she was probed about how she was coping emotionally since she had not alluded to this and her response was also similar to participant 5’s statement quoted above:

“Ah no I do worry sometimes but, ah, not all that much because I know his status plus the doctor sat me down and explained that it happens.”

4.2.7 Participant 7

Main theme: Taboo and lack of family support.

This interview took place at the participant’s place of work where she also resided since she was employed there as a housekeeper to a young professional couple who the researcher had an opportunity to meet on that occasion. It was enlightening that it took place there because the researcher gained greater insight into her care-giving experience which was important in this case as she had been giving care to her son there for three years, the longest duration for all the participants interviewed. She raised the difficult issue for her of having to bath her adult son.

“To look after a grown up son who had a wife, bathing him, it’s a big job.” And *“It is difficult indeed because when he first fell ill it was too much for me to touch his body since*

he is an adult.” Although she was grateful for the support she was receiving from her employers she bemoaned the fact that she had no relatives to support her.

“What worries me is I do not have anyone I can tell what is happening to this child.” And “In our African culture we gather together for our problems.”

4.2.8 Participant 8

Main theme: Dealing with her daughter’s anger.

After sharing the difficulties of providing her daughter with the food she desired and transport to go to the clinic as well as the physical strain of care-giving this 58 year old mother talked about how she found it hard to deal with her daughter’s anger towards her.

“What is also difficult is that the person (referring to her ill daughter) has ----- has ----- anger. If you look after her well, if you do good things to her, she doesn’t like you.” And in reference to her daughter telling relatives that she is not being cared for well:

“That upsets me because I will be doing it with a good heart knowing that there is nothing my child can do, that she must do well but she is not even thanking me.”

4.2.9 Participant 9

Main theme: Overwhelming financial difficulties and care-giver to multiple patients.

Besides giving care to her ill sister this single mother of three was also had two HIV nieces in her care. Her main concern was increased financial demands and she was struggling to cope.

“Yes, ok, umm.... I can talk about the issue of what I can help her with. I am working but hey, I can’t really help her because she needs a lot of things so much that sometimes I fail to do it. Sometimes she can choose food, whatever, and maybe at that time I would have bought food that is adequate for the family but then she can say she doesn’t want it, she wants something else when I won’t even have a cent. Myself I am--; I am a single parent, my husband died in 2000.” And

“I have 3 children. So I look after my sister who is ill; I also look after her child who is HIV positive. She is 4 years old and is ill. She also needs assistance. I am also looking after my brother’s daughter who is 13; she is also HIV positive so I have three HIV positive people in my house. It is so difficult for me that I fail to cope.”

4.2.10 Participant 10

Main Theme: Frustration and helplessness.

This participant was extremely distressed by the fact that her ill nephew was making demands that she could not meet, she was not sure if he was mentally confused or not. This combined with the financial burden were too much for her:

“What he wants to do, some of the things ah, you can’t get it because since he is ill; you don’t know what he wants or doesn’t want. Sometimes you can do something good for him but he can say he doesn’t want it anymore, he doesn’t want.” And

“So when you see that he is asking for something you don’t have, what do you do? My heart hurts and I cry.” She had this to say about her lack finances:

“Not having enough things, you don’t have----- . Then you worry about what you can do about it, that’s troubling, that’s troubling, that’s troubling. She was so distressed by it all:

“Those who didn’t give birth are better. They don’t see all the things we are seeing. They only cry that, “Ah people I am hungry” and that’s all.”

4.2.11 Participant 11

Main theme: Distress at seeing her daughter suffering.

This mother was very expressive about the pain she felt at seeing her daughter in physical pain. Most of the participants did not voluntarily talk about this aspect of care-giving but the researcher found this lady to be most explicit about that. Her opening sentence was:

“Firstly, it’s not easy, really, to see your daughter’s condition deteriorating day after day. So you develop a stress. Also because at times you find yourself crying. As it is I think now, ah, it’s becoming more difficult for me.” Unlike the other participants she did not focus on financial or physical difficulties instead she highlighted the emotional burden:

“She is now a baby and ah if she has regressed to become a baby, you know what I mean about that. But right now ah it’s hard. And you also find that she will also be feeling pity for you because what she does she does it unwillingly, just like that. She can piss herself so it’s upon you. When you look at her watching you”

4.3 Composite analysis of all interviews

All the interviews were analysed together and the emerging themes were identified.

4.3.1 Financial issues

Given the economic challenges facing Zimbabwe it was not surprising that financial difficulties were raised by all participants except one. The financial constraints were due to several factors most of which were expressed by the majority of the participants:

Greater demand for resources because of the illness

"I do not have food or soap for washing her soiled linen" and "Isn't it when the linen gets washed everyday it becomes old very quickly".

Nutritional needs of the ill person

"Sometimes she can choose food , whatever, and maybe at that I would have bought food that is adequate for the family but then she can say she doesn't want it, she wants something else when I don't even have a cent."

Transport needs

"So when the day we have to take her to the hospital comes and she is not able to walk, how hard it is for me! Starting to look for transport to carry her-to take her to hospital. The money for the fuel is what's hard to find, they charge a lot."

Lack of employment

"So it is a problem not to have an income when you are caring for someone who is ill because how do you help them and yourself?"

Breadwinner is the ill person

"But there is nowhere for me to get the food. My source for food was this daughter of mine who is now ill; she also needs help now."

High inflation

"Ah, hee hee! (laughs) What we saw today! I am shocked that the \$5 000 that we were paying for kombis will be increased to \$10 000 next week. So now it's hard."

Selling property

"I try to sell my things. My house may soon become empty even though I am still alive and living in it".

Other dependants

Four of the care-givers mentioned having the extra burden of looking after either the ill person's children or orphans, some of whom were ill.

"I also have other family members who are ill at home. They all expect me, their grandmother to do something about it, to do something about it."

Medical needs

Three participants admitted to being unable to provide the required medical treatment because of the added expenses.

"Yes the drugs are so expensive and sometimes I can't afford some of the drugs the doctor says we should buy."

4.3.2 Care-givers' physical/health issues

These were issues raised by the participants relating to care-giving and their own physical health or condition.

Pre-existing conditions

"There was a time my sugar and BP were very high because I was feeling that my mind was not working right".

Age

"Secondly when one is as ill as she is, it is difficult to lift her, I am old, am very old."

Tiredness

"Yes but even during the day I always find that I'm always asleep, I sleep, myself always I sleep. I sit down I'm asleep, at night I sleep."

Disturbed sleep

"Ah because if she doesn't sleep well, you also can't sleep, you keep waking up when you watch her trying to get up and failing, saying she has no power, ah that is what I am faced with."

Psychosomatic symptoms

"I had sharp pains, I felt sharp pains when I was forcing her to eat, I just felt a stabbing pain ah and then my arm could no longer work. Now how can you help someone else who is helpless when you have also become helpless?"

Physical burden of care-giving

"Looking after a grown up, a grown up woman who can't wash for herself, who can't cook, who can't bath herself. But in the past you would pour water in the dish she'd bath herself. But these few days of this week she can't, she can't even wake up. I just have to help her and lift her off the bed. It is difficult because (pause) it would be easy if when I'm going out she would just do everything for herself but she can't so I have to think everything for her. Dress her, wash for her, iron her clothes, and cook what she wants. "

Fear of contracting HIV

"Gloves are not available; the money to buy the gloves is also unavailable. What do you do? You just wash with your bare hands and end up catching HIV as well and also become ill. Because I see that in Nkulumane where a lot of people have taken care of their ill relatives without any protection they have ended up with the whole household dead leaving the young ones alone."

Weight loss

“I worry a lot – this is not my normal weight. I am bigger than this but if your heart is constantly troubled you end up getting stressed because caring for the ill is tough.”

4.3.3 Care-recipients’ physical/health related issues

These were specific issues that were raised by the care-givers concerning the health of the person in their care.

Incontinence

“Hmm, it is er is quite difficult should I say: er, the fact that for the previous one month er she couldn’t even go to the toilet by herself and I could take her to the toilet, sometimes if I came too late I’d find her messy, then I’d have to remove everything and wash everything. That’s what I am doing right now.” Another participant had this to say about the incontinence, *“So she wets herself in bed so hey, the situation is difficult for me.”*

Skin lesions

“I used to sleep with her at that time. I would wake up covered in her skin until I said it was better to separate what? The bed. So she was to sleep alone in case I also contracted the condition.”

Poor appetite

Besides the financial difficulty in providing the more nutritious and/or the preferred food required by the ill person, the poor appetite often associated with AIDS seemed to cause a lot of distress probably because of the belief that the anti-retrovirals prescribed would not work if the person was not eating well or vomiting.

“That she doesn’t eat, if someone is not eating you know it means that there is no ----, it means that she won’t improve. Even if she gets the medication, where will they go? Isn’t it they will be harmful to her again if she is not able to eat. So that’s how you end up forcing her to eat, ah that is what worries me!” And from a different participant, *“That is the problem that worries me a lot because if she spends the day without eating -----, I cant ----, the pills the tablets cannot work.”*

Fluctuating symptoms or lack of improvement

“Sometimes when she has had a bath she gets so tired that I start worrying what the tiredness is all about and why it does not go away. Sometimes she washes without any problem but other times she comes out of the bathroom breathless and asks me not to

apply lotion on her body because of the tiredness. So when she is like that it worries me why she is so tired.”

Deteriorating condition

“Firstly, it’s not easy, really, to see your daughter’s condition deteriorating day after day. So you develop a stress.” And from another participant *“Because two days ago -----, as from yesterday she cannot help herself in any way so all that is on you as a mother and really just think of it. (Long pause). She is now a baby and ah if she has regressed to become a baby, you know what I mean about that. But right now ah it’s hard.”*

Poor mobility

Lack of ambulation was also a source of frustration.

“Even the way of taking him to hospital, people, it’s hard for me.” And *“Ok, coming to the issue of transport when we are going to the hospital. The issue of transport is very hard for me hey! Her legs are swollen, she can’t walk, and she has cracks under her feet.”*

Mental problems

There were two participants who were caring for patients with mental confusion. Although it is well known that carers of people with mental problems face additional challenges one of these two participants did not explicitly express this but the other one was clearly frustrated by the behaviour of the person they were giving care to especially since she was not certain that he was confused.

“What he wants to do, some of the things ah, you can’t get it since he is ill; you don’t know what he wants or doesn’t want. Sometimes you can do something good for him but he can say he doesn’t want it anymore, he doesn’t want.”

4.3.4 Religious issues

All but one participant mentioned God during the interviews. Some of the comments seemed to be casual, the ones which many people often make without it necessarily being a true reflection of their religious standing. However with four participants mentioning God three or more times and one of these mentioning Him seven times it can be concluded that religion has an important role in the lives of these care-givers.

Resignation to the will of God

This seemed to be the general sentiment as indicated in the following statements made by three different participants, *“I feel pity but there is nothing I can do. Nothing can help me*

to make her well again unless God makes her well. Me, there is nothing I can do.” “I realised that is what God had has given me there is nothing I can do since the wife ran away.” Finally, “Ah yes, if God decides to take him, he can take him. What can I do?”

God as a source of strength and help

“Only God is helping me and I am truly grateful to him. I would have long died from BP because of thinking too much.” And from another participant, “I find it from God. God gives me strength.”

God’s goodness

“God is good to me because somehow I find myself with the transport”. This particular participant mentioned the goodness of God three times.

Praying for God’s help

“I will be asking God for her to survive” and from another participant, “That’s all that worries me, wondering when God is going to intervene so that she will start taking ARVs soon, which will hopefully make her strong again.”

Complaining is a sin to God

“Ah, the work is very hard because looking after the ill is difficult. He wants this and then he says he doesn’t want it and wants something else. At times you end up saying “Ha I am suffering.” and at other times you end up saying “People this is a sin to God” so you get up and do what he wants you to do. But it will be painful to you in your heart as you will be wishing that he could be able to do what he wants for himself.”

Questioning God

“I’m not lying to you but when I think of all this nearly every day I start to cry, asking God or is it Satan why my daughter is going through all this when some people don’t do so.” and, “She is helpless there and you cannot help her as well so what you can do is to cry and ask God for help saying ‘God please help me, what did I do wrong?’”

4.3.5 Family issues

These issues pertain to the family, most of which exacerbated the burden of care-giving.

Orphans and other dependants

Four of the participants mentioned having either orphans or children of their adult care recipients or both in their care. Some of these were ill from HIV/AIDS. “I also have orphans. I have many orphans and the one left by his mother n 2004 is always ill” And “I have 3 children. So I look after my sister who is ill; I also look after her child who is HIV

positive. She is 4 years old and is ill. She also needs assistance. I am also looking after my brother's daughter who is 13; she is also HIV positive so I have three HIV positive people in my house. It is so difficult for me that I fail to cope."

Previous losses to HIV

Several of the care-givers mentioned other relatives who had died of AIDS and seemed to relive these losses through the care-giving process. *"Some day one eye will be swollen and the next day the other one will be swollen. I worry a lot about that. I wonder if it is going to get worse or improve because my young sister who came after me died. She started with swollen legs and it went up to her abdomen and she did not survive."* And from another, *"Yes, isn't it the first one died from the illness (HIV/AIDS), the second also died of the illness and so did the third one. My granddaughter also died of the illness and she left an infant whom I fostered from one year of age and now she is 4. So when my grandson's partner arrived that day I was alarmed because I said to myself, "I am going through the same difficulties I had been through in the past."* This lady also shared that both her remaining children were living with HIV.

Abandonment

Three care-recipients had been abandoned by other family members because of the illness, two of whom had been deserted by their wives. One care-giver was taking care of her grandson's girlfriend because her own family had refused to look after her, *"I sat down alone contemplatively and asked myself that if I refuse to look after my grandson's partner how is he going to manage on his own. I knew I didn't have enough money to look after her but since I already had other ill people I was caring for, I decided to take her as well."* There was a mother who struggled to deal with the taboo of washing her adult son since his own wife had abandoned him, *"It is difficult indeed because when he first fell ill it was too much for me to touch his body since he is an adult."*

Support

Although several care-givers stated that they had little or no financial support from their families this was mainly due to poverty, unemployment or previous losses to AIDS. However, there was one mother caring for her daughter who was very upset with her other children for not supporting her financially since the daughter she was looking after had been her breadwinner, *"Actually it is better to say I don't have any other children to be honest because you can only consider a child that assists you in some areas."* In contrast to that, the mother mentioned above who was looking after her adult son, who was her

only child, felt she had no one to support her emotionally. She was a widow and both her parents had also died, *“What worries me is I do not have anyone to tell what is happening to this child.”* She also made this powerful statement, *“In our culture we gather together for our problems.”*

However there was only one care-giver who talked about the assistance she receives from her family, *“But anyway my, my relatives, my brothers and sisters they help me a lot. Whenever I tell them that I have this problem they come forward and help me.”*

Disclosure

Interestingly, both of the spousal care-givers interviewed were the only raised ones who raised the subject of disclosure. One of them said *“He would just sit down if he felt like it while panting heavily at the same time so much that the elders who did not know what was wrong with him, isn’t it he had not told them his status? ”* And the other one had this to say *“The problem was telling our children what the pills were for.”*

Property rights

One care-giver complained that her ill sister’s in laws had taken blankets amongst other that she needed to use to take care of her, *“Ah! The husband’s relatives took blankets and left her with nothing.”*

4.3.6 Emotional issues

Most of the participants did not readily talk about the emotions they felt on witnessing the suffering of their ill relative so the researcher had to probe some of the participants in order for them to share their feelings about this. They however freely discussed the emotions they experienced about the challenges of the care-giving process.

Worry, helplessness, despair

It is not surprising given the harsh economic climate in Zimbabwe that this challenge elicited powerful emotional responses ranging from worry, helplessness and despair.

“Because the stuff you need for protection is not available, they are too expensive. In 1994 everything was easy. Now it is hard, you see, it’s very hard. Sometimes I despair so much that tears just flow on their own because I would be feeling so troubled. And from another participant, “Not having enough things, you don’t have-----. Then you worry about you can do about it, that’s troubling, that’s troubling, that’s troubling. Where can I go to now?” Deteriorating health of the person in their care also elicited the same emotions of worry, *“I start worrying what the tiredness is all about and why it does not go away”* and

helplessness, *“What am I supposed to do now? I can’t say to him give me the illness so that you can have some rest. It can’t happen! So the burden is his alone.”* and despair, *“Those who didn’t give birth are better. They don’t see all the things we are seeing.”*

Emotional pain and sadness

This was related to the suffering they saw their loved ones in their care going through. A mother had this to say, *“It pains my heart very much because this is my only son, I do not have a daughter. So when it gets to the stage that he is not well I feel really ill.”* And from another mother, *“Firstly, it’s not easy, really, to see your daughter’s condition deteriorating day after day. So you develop a stress. Also because at times you find yourself crying.”* An aunt had this to say, *“But it will be painful to you in your heart as you will be wishing that he could be able to do what he wants for himself.”* One mother simply stated, *“I feel sad.”*

Overwhelmed

Some of the care-givers shared on how they found the demands quite stressful.

“One day you can end up taking a rope and hanging yourself. People will then say so and so went crazy and hung herself when it is all from being overwhelmed by all these problems on one person. It will be too much, seriously. And from another who was caring for her ill sister as well as HIV positive orphans, *“It’s so difficult I fail to cope.”*

Anger

This was expressed by the mother who felt unsupported by her other children while she was giving care to her daughter who prior to her illness was her source of financial support, *“Actually it is better to say I don’t have any other children to be honest because you can only consider a child that assists you in some areas”* she then went on to say angrily, *“So I don’t really consider my other children. I don’t, no I don’t.”*

Hope and hopelessness

When probed about how they felt about the prognosis of their loved one’s health two of the participants expressed hope in them recovering because they knew people who had recovered *“Ah I see people who have been very ill surviving. So I have hope that she will survive, maybe as she takes the ARVs she will survive.* In contrast one mother’s hope was fading because her daughter was very ill, *“Ah it’s such that you lose hope.”*

Anxiety

This was largely related to uncertainties about the care-givers’ life circumstances such as job security, finances and assistance with care-giving for one participant in particular who

was employed; her daughter had been assisting her with the care-giving duties but was due to return to school. A mother who was facing the possibility of losing her housekeeping job had this to say *“Right now I am in a difficult position, sometimes I do not know what is going to happen, I don’t know if we will have to leave before we know which tablets he is going to take.”* The delay in commencing anti-retrovirals was also a cause for anxiety for those care-givers whose ill relatives had not yet been commenced on them, *“That’s all that worries me, wondering when God is going to intervene so that she will start taking ARVs soon, which will hopefully make her strong again.”*

Dealing with the emotions of the patient

Three of the participants shared the difficulties they had with coping with the emotions of those in their care. One of them talked about her ill daughter’s anger and unappreciative attitude towards her despite all the work she was doing, *“That upsets me because I will be doing it with a good heart knowing that there is nothing my child can do, that she must do well but she is not even thanking me.”* This is in contrast to the other two who talked about the anguish of seeing the emotions of those they were taking care of, one of them had this to say about her daughter and how she appeared to feel when she was cleaning her up after soiling herself, *“And you also find that she will also be feeling pity for you because what she does she does it unwillingly, just like that. When you look at her watching you”* *Clean her up, do this and that, clean up, wash her laundry you can see that she is getting stressed up so that you also end up stressing and sometimes, sometime last week I feel sick.”*

4.3.7 Appraisal of the care-giving role

Five participants talked about their perspectives on how they viewed their care-giving role.

Sense of responsibility and obligation

There was a combination of a sense of responsibility and obligation which is typified by this response from one mother, *“There is nothing I can do because she is my child and there is no one else who can look after another person’s child.”* And *“I sat down alone contemplatively and asked myself that if I refuse to look after my grandson’s partner how is he going to manage on his own.”* Despite this sense of responsibility and obligation as well as the various challenges of the care-giving experience outlined above, the participants still had positive things to say about the experience.

Gratification

It is not unusual that care-giving is sometimes associated with gratification for the care giver in spite of the burden of the experience, *“The experience of looking after my ill relative is painful but at times I am happy that I am able to look after her as there is no one else to do this except myself, her grandmother.”* Related to this phenomenon of gratification, two participants specifically mentioned love as an important factor in carrying out the care-giving duties, *“The love to take care of my mother’s child, my sister.”*

Lack of blame

The mode of transmission of HIV could lead to blame and stigmatisation but this was not evident in any of the interviews with 2 participants voluntarily stating that they had neither feelings of blame nor hard feelings towards the person in their care, *“But it’s only that it’s difficult but I don’t blame anyone, I don’t blame her. I just have to look after her.”* And *“I will not be upset about the difficulties of looking after the ill person.”*

Coping

It is interesting that four participants who had also mentioned the varying psychosocial difficulties of care-giving detailed above still explicitly stated or implied that they were coping with the situation, *“I am coping but it is difficult but I am coping, yes.”* And from the only male participant, *“but when it comes to looking after my wife it is hard but I am coping because of all the counselling I have had as you can see.”*

CHAPTER FIVE

5 DISCUSSION

5.1 Demographics

Only one of the eleven participants was male. This is not surprising since the care of the ill has always been the responsibility of the female members of the family who are regarded of the two sexes as the nurturers and carers. The care of AIDS sufferers has not been an exception and has also largely been done by women^{44, 45}. Studies from Africa that did not specifically focus on care-givers of either gender also had a significant dominance of women as the primary care-givers^{17, 20, 21, 23, 25, 46}. In contrast, a review analysis of several studies conducted in different cities in America showed that there were more males than females involved in care-giving in some of the communities⁴⁷. The reason for this is that there were gay communities in the areas under study and the tendency in those communities is for the lovers or gay friends to be involved in the care-giving of the AIDS patients. This was highlighted in a large American study that sampled central cities and the nation as a whole²⁶. The results showed that in the central cities male care-givers were marginally higher than the females and the converse was true when the national figures were analysed but in addition to that a much higher percentage of gay and bisexual men had been involved in care-giving compared to heterosexual men in the central cities. The researchers concluded that the higher prevalence of male care-givers in the central cities was due to care-giving amongst gay and bisexual males.

The age range of the care-givers in this study is 34 to 69 years with 7 of the women being 50 years and above. This is consistent with literature from Africa which has shown that AIDS care-giving has become the responsibility of young girls and older women over the age of fifty^{17, 20, 21, 23, 25, 46}. Children were excluded from this study so only adults were interviewed but one care-giver did mention that her young daughter was playing a supportive role in providing care to her ill sister. The main reason why the elderly are playing a major role in AIDS care-giving in sub-Saharan Africa is because of the high AIDS deaths in this part of the world which has resulted in a shift of the population demographics⁴⁸. HIV prevalence is highest from the late teens to the mid thirties, the section of the general population that is the most sexually active which in turn results in

significantly increased mortality rates in the 20 to 45 years age group, a group that prior to the AIDS epidemic had the lowest death rates⁴⁸. Therefore in countries where there have been high AIDS mortalities, such as Zimbabwe, the elderly members of the family have come to bear the brunt of care-giving because some of the younger members of the family have succumbed to the disease⁴⁴. The other reason that the elderly have been involved in care-giving is because the prime-aged as the economically productive members of the society especially in urban areas, such as in this study, are often formally employed and are therefore unable to be primary care-givers leaving the elderly members of the family to provide care to the ill.

Eight of the eleven patients in this study were being taken care of by their blood relatives, five of whom were mothers and this is unsurprising because of the close nature of the relationship and that mothers are the default carers of their offspring during times of distress. Other blood relations were two sisters and an aunt. The bulk of AIDS care-giving in Africa is provided by the family often by blood relatives⁴⁹ in particular mothers as shown in one study mentioned in the literature review conducted in rural Malawi where nine of the fifteen care-givers interviewed were being mothers of the adult children and one from Botswana²⁰.

Of the three non-blood relations in this study only one of the two spousal care dyads was a wife giving care to her husband which was rather surprising to the researcher as she expected to find more wives than that giving care to their husbands, notably only three of the patients represented by the eleven care-givers in the study were male. None of the fifteen care-givers studied in the Malawian study mentioned above were wives²⁰ whereas in a rural Tanzania study 13 of the 60 caretakers were giving care to their husbands and in another study from Congo all 80 women in the study were taking care of their spouses²². In comparison, two separate American studies that specifically focused on female care-givers and therefore excluded male care-givers taking care of their gay lovers also found that most of care was done by relatives; 81% and 76% of the care givers were relatives with 28% and 35% respectively being mothers and 14% and 26% respectively being wives or partners^{18, 27}. The reason there were few wives as care-givers to their husbands in some of the African studies including this one could be because of the higher prevalence of HIV in women due to their biological, socio-cultural and economic susceptibility to contracting

the virus^{44,50} which may result in earlier mortalities than their spouses particularly in those countries hardest hit by the epidemic such as Zimbabwe. In the American studies probably part of the reason was that a large number of the AIDS patients were gay and were therefore unmarried¹⁸.

The vulnerability of females to HIV infection may also explain why eight patients out of the eleven AIDS sufferers in this study were female. Another surprise for the researcher was the fact that two of the three male care-recipients had been abandoned by their wives, a phenomenon also reported in a Ugandan study investigating the plight of older care-givers²³. Prior to conducting the research, the researcher felt that women were not likely to abandon the care of their ill husbands so it was an interesting finding for the researcher.

The duration in care-giving ranged from three weeks to three years while the inclusion criterion in terms of duration was a minimum of two weeks. Three studies from the Americas mentioned in the literature review stated duration of care and this ranged from two weeks to an astounding fourteen and a half years for the three studies combined^{18, 19, 24}. Given the poor access to anti-retrovirals in the study country as well as the inadequate general health care which contribute to the high mortalities associated with AIDS in Zimbabwe it was reasonable to include care-givers who had been giving care for a shorter period than one would have desired because of time limitations in completing the study. There was important information obtained from all the participants even from those who had been giving care for the relatively shorter periods.

Some of the studies stated hours of day spent in giving care as a variable in the demographics^{17, 18} while others also assessed the type of care provided^{17, 19, 22}. This study, by having an inclusion criterion of care-givers providing assistance with activities of daily living and the fact that all the patients in the study had Kanofsky scores of 70 or less means that the patients were quite dependent on the care-givers and therefore the former were spending significant time in care-giving.

5.2 Themes

5.2.1 Financial issues

Lack of financial resources was a big concern for most of the participants. All the participants except one talked about the lack of money that they required to meet the various needs and demands of the care-giving process. The one participant who did not talk about financial difficulties was the only male participant recruited and that interview was more of a monologue on how they came to test for HIV and to commence ARVs, he did not talk about the care-giving process *per se*.

The prevailing economic hardships in Zimbabwe of high inflation and lack of employment, which were often cited by the participants, were a source of great distress for these care-givers because of financial lack. All the studies that were reviewed from Africa also revealed that poverty had a major impact on the psychosocial well being of carers^{17, 20, 21, 22, 23, 25, 46}. In countries with high prevalence the HIV/AIDS epidemic has had devastating effects on both the national economy and household income. Household income is affected in several ways^{51, 52}. Firstly, there is loss of income when the ill persons are no longer able to contribute to the household income as evidenced by the deep distress of an elderly chronically ill mother in this study who was a carer to her daughter who previously was her sole bread winner. This mother had resorted to selling her household goods to raise some money to provide for her ill daughter a practice which was also reported by other AIDS care-giver studies^{23, 25}. Secondly, the carers sometimes are unable to pursue income generating projects because of the demands of care-giving or because of the fact that most of the care is done by the elderly who are retired and therefore have limited financial means in any case^{46, 53} the older care-givers in this study were mostly unemployed.

Thirdly, the financial demands directly related to giving care are significant and those mentioned by the participants include special foods, transport to and from the hospital, washing detergents, bedding, medical expenses; lack of which distressed the care-givers immensely since they felt this compromised the health of the ill as reported in other studies^{20, 46}. Lastly, previous family losses to AIDS further impoverishes these households because less income is remitted as well as having depleted the family from care costs and

other expenses such as funerals, linked to this is the added burden the orphans resulting from these deaths. Five participants mentioned previous losses to AIDS and four had orphans in their care. Care-givers from Brazil and minority communities from North America also cited financial difficulties as a source of stress^{24, 26}.

5.2.2 Care-givers' physical/health issues

The older care-givers expressed some concerns about their physical well being which in turn would also have an impact on their psychosocial well being. They complained of pre-existing conditions such high blood pressure, diabetes and arthritis which are common in the older population in general but their concern was that the burden of care-giving was worsening these conditions. Although they did not offer any objective proof of this exacerbation of their chronic conditions the researcher felt that they were genuinely concerned about the effects of care-giving on their health. The limited financial resources did not allow one mother with diabetes to adhere to her diet and that caused her great distress. Given the level of poverty reported by these care-givers it is very likely that they were not able to seek medical attention for their chronic conditions. 82% of Latina family AIDS carers in a study conducted in America also reported experiencing chronic conditions such as asthma, hypertension and diabetes²⁷.

The participants also reported on tiredness which could have been a result of several factors such as the physical exertion of care-giving, disturbed sleep from worrying and from getting up at night to attend to the needs of the patients or their children and possible depression. Some carers felt overwhelmed by the many chores they had to do and the physical strain of carrying and bathing their adult children. Exhaustion was found to be the main complaint of elderly care-givers in Botswana¹⁷ while another study from the same country showed that most were not strong enough to meet the physical demands of care-giving. One mother mentioned that she had consulted a doctor for the sharp pains she experienced while force feeding her daughter and was told the pains were due to stress. Unsurprisingly other AIDS care-giver studies have also reported on psychosomatic symptoms which included headache, abdominal pain, chest pain and anorexia^{22, 23} while some of the symptoms such as backache could be related to the physical work of care-giving. Loss of appetite and weight loss which was reported by one participant could be from a combination of poor nutrition, worrying and physical strain.

The demographic information collected at the beginning of each interview included the HIV status of the carer and all but two participants did not know their HIV status. However, some participants raised their concern about their status during the interview. Although one participant mentioned that she had observed that many care-givers in her community had succumbed to HIV/AIDS thereby implying that they had contracted it during the care-giving process, the researcher felt that they carried out their care-giving duties diligently despite not having any protective measures for prevention of contamination. Lack of resources was cited in this study as the reason why they were not using any protective devices such as gloves while in one of the studies from Botswana mentioned above the participants felt care-givers succumbed to HIV because of lack of care-giving knowledge and inadequate care packages⁴⁶. It was found that elderly care-givers in the other Botswana study did not use the care package they were provided with because they felt that using gloves would imply that they do not love the person in their care¹⁷ which is in contrast to the response of care-givers in a Namibian study who expressed anger at the risk that they were exposed to²¹.

5.2.3 Care-recipients' physical/health issues

Some participants mentioned some physical conditions that were experienced by their care-recipients that made care-giving more difficult for them and these included incontinence and skin problems. Lack of protective gloves, soap and adequate bedding as well as the increased work load were stated as reasons why incontinence was a particularly difficult condition to cope with besides the unpleasantness that is inherent in the cleaning up. Anorexia is a common symptom in AIDS patients and it caused a lot of frustration for the care-givers in this study because they felt that the ill in their care would not improve if they did not eat well. Besides the reluctance of the care-recipients to eat properly, the inability by the care-givers to provide the nutritious foods requested or required by the ill was also a big stressor. Some expressed the frustration they felt when the ill person refused to eat or vomited the food they would have requested. This frustration emanating from the inability to provide a good diet is consistent with findings from other studies and can be the cause of tension within the care dyad^{20, 21}. Frustration was also expressed by the two care-givers who had mentally confused patients in their care because it was difficult for the patients to cooperate with the care-givers and they also made unrealistic demands. AIDS dementia is fairly common and is a big challenge for care-givers²⁸. Poor mobility

was also a significant problem for the care-givers because this increased the work load of care-giving and care costs because of the need to pay for suitable transportation to and from the clinic. Finally, the deterioration or lack of improvement in the overall condition of the loved one in their care was very distressing to the carers and a cause for great despair as this probably meant they were dying. These emotions were therefore part of anticipatory grief²⁸.

5.2.4 Religious issues

All but one of the participants in this study mentioned God at least once with some doing so three or more times in the course of the interview. The researcher felt some of the comments were merely casual and did not necessarily reflect their religious convictions while others seemed to portray a strong belief in God and a source of the strength they required to overcome the challenges of care-giving. Their comments on God mainly reflected a resignation to the will of God which may be a result of what they felt was the hopelessness of the situation they found themselves in while others reflected God as a source of strength and testified to his goodness in helping them cope with the challenges they had. Some care-givers questioned why God was letting them face such difficult times and others felt it was a sin to God to complain. 57% of AIDS care-givers in one study found religion to be a comfort and felt that their faith in God had increased as a result of the illness while 17% no longer went to church or worshipped at home because of care-giving demands¹⁷. Female care-givers caring for cancer patients in India went through different stages of religious views starting with questioning God, anger towards Him and finally hope and belief in His compassion⁵⁴.

The researchers of the Indian cancer care-givers study recognised a range of “cognitive mechanisms of coping” based on religious belief frameworks in their interviews⁵⁴. Firstly, there was the belief of being tested by God which meant that they had to hold on to their faith despite the difficult situation they were in and perform their care-giving duties to the best of their ability and hence kept them motivated. This belief is exemplified in the present study by one care-giver who said she believed God was testing her love for Him. Secondly, there is the belief everything is God’s plan and His plans are good; this may be the reason why the participants in this study talked about allowing God’s will to be done. The third belief that emerged from the Indian study which is illustrated in the current study

by one care-giver who talked about asking God to intervene so that her daughter could commence ARVs soon so that she could survive is what they called “self-talk strategies” which is commonly known as prayer. The fourth belief they described is “mental simulation” which seeks to find comfort by imagining a worse scenario than one’s present situation and attributing this better situation one is in currently to God’s goodness, this strengthens their hope in the future. An example of this in this study is a care-giver who remembered how she had managed with God’s help to nurse three people at the same time she had a broken arm; she stated that this gave her hope that she would overcome the situation she was facing presently.

5.2.5 Family issues

There were family related issues that had an impact on the care-givers’ role; most of which exacerbated the care-giving psychosocial burden. The main problem was the extra burden they had with taking care of the orphans or children of the person they were giving care to or both. Three of the four participants who had orphans or other dependents in their care were grandparents while the other one was a widowed sister giving care to her ill sister, her sister’s children, her late brother’s child and her own children. One of the grandparents had orphans left behind by two of her late children, some of whom were ill as well as the child of the adult patient in her care. The high mortalities associates with AIDS in Zimbabwe have resulted in this huge problem of orphans⁷. These orphans therefore often come under the care of grandparents because of the deaths of younger members of the family such as aunts and uncles^{17, 23, 55, 56} who would have been better able to take care of them. This increases the financial burden of care-giving on the grandparents who are often not economically productive²³. The care-givers with orphans all talked about the hardship of providing for the children and of schooling them. Some also had the added burden of HIV infected children which increased the work load and medical expenses as reported in a Ugandan study²³; the widowed care-giver mentioned above had three HIV/AIDS patients in her home. Previous losses of family members to AIDS not only affected the psychosocial well being of care-giving by reducing the family income or by producing orphans but also emotionally. Some of the participants stated that they were distressed by witnessing yet another loved one suffering from AIDS because they feared that they would also die particularly when they were experiencing the same symptoms as the person who had died.

Abandonment of ill relatives also presented difficulties for these care-givers with three of them reporting abandonment of people in their care. Two of the three male patients represented in this study had been abandoned by their wives, a practice also reported on in another study²³ which was unexpected since the cultural expectation is that women are the ones who are more likely to be abandoned by their husbands and their families⁴⁴. This abandonment of husbands created a special challenge for a mother who had to wash her adult son since it is a big taboo in the African culture for a mother to touch the naked body of her adult son. This care-giver said she had found it extremely difficult but felt more comfortable with time. Another care-giver felt compelled to take in her grandson's ill partner and her child since her own family had refused to look after her even though she had four orphans in her care at that time and had very little income. Related to this abandonment of ill spouses is the practice in some families of sending away ill women after the death of the husband and keeping the family property for themselves^{56, 57}. One care-giver in this study complained about how her sister's late husband's family had taken all the blankets from her and she could not afford to provide her with adequate bedding.

From the depth of despair that the care-givers expressed about the financial burden of care-giving it seemed that generally most of the care-givers had no financial assistance from either family or friends and some of the care-givers actually stated that there was no one to help them financially because their relatives had no means to do so and they all appeared to accept it. This was most probably due to the fact that they realised the economic hardships facing the majority of Zimbabweans. However, one mother expressed bitterness at her other children who were not supporting while she was giving care to her daughter who prior to the illness had been her sole provider. In fact the essence of that particular interview was all about her suffering and nothing at all about the suffering of her ill daughter. Two participants admitted to receiving considerable financial assistance from employers and relatives respectively. Besides the lack of financial support, lack of emotional support was also a problem with one widowed care-giver expressing anguish at not having relatives to share her problems regarding her son's illness.

The two spousal care-givers in the study were also HIV positive and were concerned about disclosing their status to other relatives. The husband who gave a narration about how they

came to test for HIV worried about when they should tell their children while the wife whose husband was mentally confused was concerned about his parents who did not understand the condition of their son. The researcher supposes that their reasons for not disclosing their status was not related to fear of stigmatisation as revealed in a 2006 Ghanaian study⁵⁸ but from an attempt to spare their close relatives from the pain of dealing with the diagnosis. Unlike the Ghanaian study where stigmatisation was a major theme, none of the care-givers in this study suggested that stigmatisation was a problem for them.

5.2.6 Emotional issues

The researcher found that the majority of the participants did not voluntarily talk about their emotions regarding the experience of seeing their loved ones suffering or their prognosis. They freely shared on the challenges of meeting the needs of the ill person and this evoked strong emotions of helplessness, worry and despair. Some of the participants cried during the interview while others admitted to crying often because of the difficulties they were encountering to make ends meet. Care-givers in American studies reported about minimizing their own concerns in order to focus on the care-giving process^{18, 28} and that could be the reason why the participants may have been reluctant to share some of their emotions. It is also likely that the difficulties associated were so overwhelming that they had become desensitised to their feelings.

Those care-givers who did verbalise their emotions concerning the suffering of their care-recipients either voluntarily or on being probed talked about sadness and heartache. It is not possible from the nature of the study to determine if some of the participants had overt clinical depression but it is likely considering the stressors they were under as well as the feelings of emotional pain that they expressed and reports of loss of appetite and weight, tiredness and sleep problems. The possibility of clinical depression was highlighted by one participant who talked about being so overwhelmed that she could end up hanging herself while another said she was failing to cope. Anticipatory grief is a possible explanation for these feelings of sadness particularly when the patient's health is deteriorating²⁸.

When asked directly about how they felt about the prognosis of the ill person in their care most of the participants said that they had hope that the ARVs would help them and make a full recovery because they had seen it happen to other people. Unfortunately the

researcher does not have the data to correlate this presence of hope to those care-givers whose care-recipients had recently commenced treatment. One care-giver whose daughter's health had recently deteriorated such that she was requiring assistance with all the activities of daily living confessed that the situation was so bad that she was losing hope. A sense of hopelessness was also reported by care-givers in Uganda²³.

Besides worrying about the health of the care-giver and the financial difficulties the care-givers also expressed feeling of anxiety related to uncertainties of the future. There were care-givers who were anxious about job security, care-giving assistance and about when their care-recipients would commence ARVs. A study comparing informal care-givers of people with AIDS and dementia found that the former were more significantly more anxious and angrier than the former³². Another study found that anger was common in AIDS care-givers and that they were angry at the disease because of the suffering of those in their care, themselves, the person suffering from AIDS and at other family givers. Only one participant expressed anger and this was directed at her children who were not being financially supportive.

Some care-givers had difficulties in dealing with the emotions of the care-recipients. One was distressed by the angry and unappreciative attitude that her ill daughter exhibited towards her despite her best efforts to look after her. Care dyad conflict has been reported in several studies and is caused by tensions arising from the mood changes of both of them^{21, 23, 46}. These mood changes are dependent on the health fluctuations of the patient and the inability of the carer's ability to provide satisfactorily. Two care-givers talked about the pain they felt when they observed that the person in their care felt terrible about being dependent on them for activities such as toileting.

5.2.7 Appraisal of the care giving role

Despite the challenges that were described by the care-givers some of them still reported that they were coping with the care-giving role. Two of the care-givers who said they were coping said the counselling they had received was helping them cope and both of them were spouses who were also HIV positive. However, one of them may have been referring to coping with the diagnosis of HIV infection rather than the care-giving while the other one was specifically referring to coping with her husband's mental condition. When

Chimwanza and Watkins asked the participants in their study what problems they were experiencing they said that they had no problems and would go on to say that the reason they had no problems was because the person they were taking care of was a close relative²⁰. They postulated that this underplaying of the difficulties of care-giving could be what they termed “courtesy bias” meaning that the participants may have felt that an admission of being troubled by the role of care-giving maybe understood as not having enough love for the person they were caring for. This might also explain why some of the participants in the current study were quick to say they were coping.

Besides coping with the care-giving a few care-givers in fact expressed a sense of gratification or fulfilment. This is similar to the responses of Botswana care-givers, 46% of whom said they were either highly satisfied (26%) or moderately satisfied (20%) with their care-giving role¹⁷. They said their satisfaction was derived from desiring to do the best for their children. The close relationship such as the one that exists between a mother and a child therefore explains why the care-givers in this study and others have reported this fulfilment they experienced with care-giving^{17,18,20}. The unconditional and sacrificial nature of the mother-child relationship also explains why some of the care-givers stated that they did not blame their children for contracting HIV. Interestingly, the only non-blood relative who was not a spouse, who also had the highest number of orphans in her care and according to the researcher had most likely the least resources actually stated that she was happy to be giving care to her grandson’s girlfriend. She was also the one who spoke the most about God so her religious beliefs could be the explanation for her altruism.

A study showed that 73% of care-givers to elderly people identified one positive aspect of their care-giving role while an extra 6.9% found more than one⁵⁹. The positive aspects included companionship, fulfilment, enjoyment, duty, the desire to provide quality of life and giving meaning to their own lives. The carers that had more positive views on their role were significantly less likely to express depressive symptoms, burden or poor health. It seems that the challenges of care-giving as described in this study are ameliorated to some extent by the care-givers’ appraisal of their care-giving role.

CHAPTER SIX

6 CONCLUSION

This study set out to find out the psychosocial impact of care-giving on family care-givers of chronically ill HIV/AIDS in Bulawayo, Zimbabwe. It was conducted at a time when the country was facing a serious economic crisis so it is not surprising that the care-givers main difficulty was limited financial resources and this caused them considerable distress. There were factors relating to the family, the health and physical aspects of the carers and the care-recipients that compounded the financial burden. The participants experienced a spectrum of emotions ranging from worry, helplessness and hopelessness, despair, sadness, feeling overwhelmed but some still had hope in the recovery of the person in their care. Their appraisal of their care-giving role was generally positive and that together with their religious beliefs may have ameliorated their care-giving burden.

Although the sample size was small the researcher was able to gain a good insight into the experience of these care-givers because of the qualitative nature of the study. However, further research utilising quantitative methodology will be required to elucidate relationships between demographic data such as age, income and duration in care and the burden of care using the various scales available to measure mental and physical well being.

Given the burden faced by these care-givers of the chronically ill AIDS the researcher recommends the following:

1. Campaigns by government in conjunction with non-governmental organisations to train and equip health workers to identify care-givers at risk.
2. HIV support groups to set up parallel support groups for care-givers.
3. Religious groups to identify care-givers in their communities and offer home visits for prayers and other support where possible.
4. Social services to be re-established that provide grants to families with the chronically ill and orphans in their care.

5. Re-establish effective home based programmes that support family care-givers. These programmes should utilise the humanitarian aid that is being offered to the country to provide the service as well as care packages and food parcels.

APPENDICES

1. Approval letters
2. Information sheet
3. Consent form
4. Demographic Questionnaire
5. Question to be asked to elicit participants' qualitative responses
6. Karnofsky scoring



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DR NG MATIMBA
PO BOX 646
FRANCISTOWN
BOTSWANA

APPLICATION NUMBER 031333TY
STATUS (DEG 01) (MMY00) PZZ

2005-03-15

Dear Dr Matimba

Approval of protocol entitled The Psychosocial impact of care-giving on the family care-givers of chronically ill HIV/AIDS patients in home based care

I should like to advise you that the protocol and title that you have submitted for the degree of Master Of Family Medicine (Part-Time) (Coursework) have been approved by the Postgraduate Committee at its recent meeting. Please remember that any amendment to this title has to be endorsed by your Head of Department and formally approved by the Postgraduate Committee.

Dr AE Wright has/have been appointed as your supervisor/s. Please maintain regular contact with your supervisor who must be kept advised of your progress.

Please note that approval by the Postgraduate Committee is always given subject to permission from the relevant Ethics Committee, and a copy of your clearance certificate should be lodged with the Faculty Office as soon as possible, if this has not already been done.

Yours sincerely

S Rann (Mrs)
Faculty Registrar
Faculty of Health Sciences
Telephone 717-2075/2076

Copies - Head of Department _____ Supervisor/s

Please note: Approval of protocol is subject to Supervisor ensuring that the candidate does a course in qualitative research and the candidate is requested to submit proof of passing to the Postgraduate Office



Faculty of Health Sciences

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Postgraduate Office

REF: 0213937Y
11/06/2006

Tel: +27 11 717-2075

Fax: +27 11 212-2119

Email: postgrad@health.uws.ac.za

Dr Natsayi Matimba
P.O. Box 646
FRANCISTOWN
BOTSWANA

27 June 2006

Dear Dr Matimba

REQUEST TO CHANGE LOCATION OF RESEARCH

With reference to your email of 8 May 2006, we are pleased to advise that your request to change the location of your research entitled: *The psychosocial impact of care-giving on the family care-givers of chronically ill HIV/AIDS patients in home based care* has been approved by the Chairman of the Postgraduate Committee.

We acknowledge receipt of your emailed confirmation that ethics approval has been granted by the University of Zimbabwe.

Please inform us when you have obtained the approval from the Medical Research Council of Zimbabwe.

Yours sincerely

A handwritten signature in cursive script, appearing to read "A McLean".

Mrs A McLean
Postgraduate Office
Faculty of Health Sciences

cc: Ms T Boogerd

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

RLM/M Matimba

CLEARANCE CERTIFICATE

PROTOCOL NUMBER M050235

PROJECT

Psychosocial Impact of Care giving on the Family of Critically Ill HIV/AIDS Patients in Home-based Care

INVESTIGATORS

Dr NG Matimba

DEPARTMENT

Dept of Family Medicine

DATE CONSIDERED

05.02.20

DECISION OF THE COMMITTEE

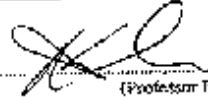
Approved unconditionally

Unless otherwise specified, this ethical clearance is valid for 3 years and may be renewed upon application.

DATE

05/02/20

CHAIRPERSON

 (A. T. WOODHEAD)

(Professor PE Cloete-Jones)

*Guidelines for written "informed consent" attached where applicable

cc: Supervisor: Dr A. Wright

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and ONE COPY returned to the Secretary at Room 10006, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I/mywe are authorized to carry out the abovesubscribed 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.

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

1-1-1 P.02

Telephone 791793/791 193/792747
Telefax (263) +1 750713
E-mail mrcz@mrczimbabwe.co.zw



Medical Research Council of Zimbabwe
Joshua Tongogara / Mazoe Street
P. O. Box CY 573
Causeway
Harare

CONTINUING REVIEW APPROVAL

Ref: MRCZ/A/1320

Date: 26 June, 2008

Dr. Natsayi G. Matimba,
University of Witwatersrand
South Africa

RE: The Psychosocial Impact Of Care-Giving On The Family Care-Givers Of Chronically ill HIV/AIDS Patients In Home-Based Care.

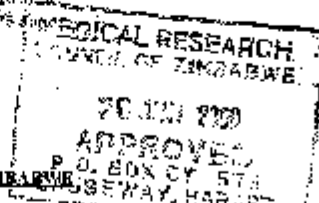
Thank you for the Application for Continuing Review of Research Activity and Progress Report that you submitted for review to the Medical Research Council of Zimbabwe (MRCZ). Please be advised that the Medical Research Council of Zimbabwe has **reviewed and approved** your application to continue conducting the above titled study. This approval is based on the review and approval of all the following documents that were submitted to the MRCZ for review.

- Progress Report
- **APPROVAL NUMBER** : MRCZ/A/1320
This number should be used on all correspondence, consent forms and documents as appropriate.
- **APPROVAL DATE** : 26 June, 2008
- **MRCZ MEETING DATE** : 26 June, 2008
- **EXPIRATION DATE** : 25 June, 2009
- **TYPE OF MEETING** : Expedited
After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Offices should be submitted one month before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING**: All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 10 working days using standard forms obtainable from the MRCZ Offices.
- **MODIFICATIONS**: Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Offices is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Offices.
- **QUESTIONS**: Please contact the MRCZ on Telephone No. (04) 791793, 791193 or by e-mail on mrcz@mrczimbabwe.co.zw.
- **Other**
- Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
- You're also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours faithfully

Proctor

MRCZ SECRETARIAT
FOR CHAIRPERSON
MEDICAL RESEARCH COUNCIL OF ZIMBABWE



PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH

Registered with the USA Office for Human Research Protections (OHRP) As an International TRP
(Number IRB00004007 10IRG0001213)

INFORMATION SHEET

CAREGIVERS' PSYCHOSOCIAL HEALTH STUDY

Hello,

I am Dr Matimba, a general practitioner working in private practice in Francistown, Botswana. I am currently studying with Wits University in South Africa and I am required to do a research project as part of these studies.

I chose to do a study to find out how relatives who are looking after ill patients who are suffering from HIV/AIDS are experiencing this process of care-giving. I have decided to study this subject because providing such care to a loved one can present difficulties emotionally to the person providing care. It will be of help to the medical profession to find out to what extent care-givers are affected by taking care of their relatives at home.

Participation in the study involves filling in a questionnaire providing some of your personal details although you are not required to provide your name. This is then followed by an interview with me. The interview will last approximately 1 to 1½ hours. Arrangements can be made to hold the interview at a preferred venue or time should you wish so. The interview will be tape recorded.

The reason you are reading this may be because you are involved in taking care of an ill relative. If you are, then I would like to invite you to participate in this study. All the information will be handled confidentially and no personal details will be shared with a third party. All notes as well as the tapes will be destroyed by me at the end of the study. In the event that the interview reveals or causes you significant distress referrals will be made for further evaluation and management.

Please note that participation is completely voluntary and that you are free to decline or withdraw from the study, please contact me at the numbers given below.

Thank you for your time.

Dr N. G. Matimba

Tel: +263 23 422 019 (cell)

GWARO RERUZIVO (INFORMATION SHEET IN SHONA)

Chidzidzo nezveutano wepfungwa nemagariro euyo anopa rubatsiro kuhama inorwara

Kwaziwai,

Ini ndirichiremba Matimba, ndinoshanda kuFrancistown, Botswana. Parizvino ndirikudzidza kuWits University kuSouth Africa. Ndinofanirwa kuita chidzidzo chekuongorora (research) hutano nemagariro emhuri ndichipedzesa fundo yangu.

Ndakarudza kuita chidzidzo chekuongorora kuti hama dzinochengeta varwere vane chirwere chemukondombero (HIV/AIDS) dzinobatikana sei mukupa rubatsiro irworo. Ndaona zvakakodzera kuti ndiongorore musoro wenyaya iyi nokuti kupa rubatsiro rwakadaro kuhama yako kunogona kukonzera kurwadziwa mumoyo wouyo anopa rubatsiro. Zvichabatsira vanoita basa rekurapa kuti vazive kudzamirwa kunoita kune hama dzirikuchengeta hama dzavo dziri kurwara dzirikumba.

Kana mabvuma kuva muchidzidzo ichi munokumbirwa kuzadzisa bepa rinozivisa zvirimaererano nemi, asi usingadikanwi kupa zita rako. Izvi zvinoteverwa nehurukuro pakati penyuni. Iyi hurukuro ichatora kuda awa rimwechete kusvika paawa rimwechete nechidimu. Munokwanisa kusarudza nguva nenzvimbo yekuita hurukuro iyi inokufanirai. Hurukuro iyoyo inotepewa (tape recorded).

Chikonzero chako chekuverenga izvi chingangove chirichekuti une basa rekuchengeta hama yako inorwara. Kana zvakadaro, naizvozvo ndinokukokai kuti muve muchidzidzo ichi. Ruzivo rwose ruchabatwa muchivande huye hapana zvakanangana nemunhu zvichakurukurwa nomumwe munhu. Mapepa ose anemashoko ehurukuro iyi akanyorwa, pamwe chete nematepi zvichaparadzwa neni pachaperera chidzidzo ichi. Kana zvikaitika kuti hurukuro iyi ikukonzere kunetseka kukuru mumoyo kuchatsvagwa vamwe vanokubatsirai vokutaura navo zviri kukunetsai.

Ndapota cherechedzai kuti kuva muchidzidzo ichi kwamuri uyezve makasununguka kuramba kana kuregedza chidzidzo ichi chero pachinhanho chipi pasina kutsanangura chikonzero chekuramba. Kana murikuda, ndapota verengai nekusiyanana fomu yokubvuma yakabatanidzwa negwaro iri.

Kana muchida ruzivo rumwe runodarika rwakanyorwa pagwaro rino pamusoro pechidzidzo ichi, ndapota ndibatei parunhare panamba dzakanyorwa pazasi.

Ndinotenda nenguva yenyu.

Dr N. G. Matimba

Namba dzerunhare: 023 422 019

IKHASI LOKWAZISA (INFORMATION SHEET IN NDEBELE)

ISIFUNDO SOKUHLOLISISA NGESIMO SENGQONDO LEMPILAKAHLE
KULABO ABANIKA USIZO

Sakubona,

Mina ngingudokotela Matimba, osebenzela eFrancistown, eBotswana. Khathesi ngiyisifundi eWits University eSouth Africa. Kufuneka ukuthi ngenze isifundo (research) ngidingisise amacebo lengxenywe yalezizifundo.

Ngakhetha ukwenza isifundo sokucubungula ngidingisisa ukuba izihlobo esigcina abagulayo bebulawa ngumkhuhlane wengculaza HIV/AIDS zizwanjani ngokwenza lokho. Ngibone kufanele ukuthi ngihlolisise indikimba le ngoba ukunakekela okunjalo komthandayo kungaletha inhlupho lokukhathazeka enhlizweni yomuntu onika usizo. Kuzanceda labo abenza umsebenzi wokwelapha bazi ukuthi nokunika kwabo usizo kuzihlobo zabo bazwanjani.

Ukuhlanganyela kulesisifundo kugoqela ukugcwalisa iphepha elilemibuzo lapho ozakutsho khona okuphathelene lawe lanxa nje kungadingeki ukuthi utsho ibizo lakho. Lokhuke, besekulandelwa yingxoxo. Ingxoxo ithatha phose ihola elilodwa kusiya kuhola

elilodwa lengxenywe. Amalungiselelo engenziwa mayelana lesikhathi kumbe lendawo ekhethiweyo okungenzelwa khona leyo ngxoxo. Ingxoxo leyo izathetshwa (tape recorded).

Imbangela yokubala kwakho kungaba yikuthi mhlawumbe kungenxa yokuthi ulomsebenzi wokunakekela isihlobo sakho esigulayo. Nxa kunjalo, ngakhoke ngizathanda ukukunxusa ukuba uhlanganyele kulesisifundo. Ulwazi lonke luzaphathwa ngemfihlo njalo akukho okuqondane lountu okuzaxoxwa lomunye umuntu. Wonke amaphepha lamazwi abhaliweyo kunye lamathephi kuzatshabalaliswa yimi ekuphetheni kwesifundo. Nxa kungenzeka ukuthi ingxoxo izezwe ikubangele usizi olukhulu kuzadingwa abanye engadluliselwa kibo ukuba ihluzwe lokuphatha.

Ngomusa nanzelela ukuthi ukuhlanganyela kuyikuzithandela ngokupheleleyo njalo lokuthi ukhululekile ukwala kumbe ukuyekela ukuqhubeka ngesifundo yiloba kuliphi ibanga kungela sijeziso ngitsho. Nxa ungathanda ukuhlanganyela, ngomusa bala njalo usayine ifomu yokuvumela elibanjaniswe lekhasi leli.

Nxa ufuna ulwazi olunengi olwedlula lolu ngesifundo lesi, ngomusa ungithinte kunombolo ezingaphansi.

Ngiyabonga ngesikhathi sakho.

Udokotela N. G. Matimba

Inombolo zocingo: 023 422 019 (cell)

CONSENT FORM

CARE-GIVERS' PSYCHOSOCIAL HEALTH STUDY

I fully understand the nature of this study which has been explained to me by Dr Matimba. I also understand I am free to withdraw from the study at any point without having to offer any explanation for the withdrawal.

Participant's Signature:

Date:

I also consent to the tape recording of the interview.

Participant's Signature:

Date:

Witness:

Date:

I, Natsayi G. Matimba, assure the participant that all the information shared with me by the participant will be analysed only by me. No personal details will be disclosed to a third party. Only the care-givers' experiences will be published and this will be done without attributing these views to any identifiable participant, hence ensuring anonymity. I will personally destroy all notes and tape recordings on completion of the research.

Researcher's Signature:

Date:

Witness:

Date:

FOMU REKUVUMA (CONSENT FORM IN SHONA)

Chidzidzo nezveutano wepfungwa nemagariro euyo anopa rubatsiro kuhama inorwara

Ndinonzwisisa zvose zviri maererano neichi chidzidzo chandatsanangurirwa naDr Matimba. Uyezve ndinonzwisisa kuti ndinokwanisa kusaenderera mberi nechidzidzo ichi pachinhanho pese pese kana ndaona kuti handikwanise ndisingamanikidzwe.

Kusayina kwemubvunzwi:

Musi:

(Participant's Signature)

(Date)

Ndinobvumazwe kuti huruko iyi itepewe (tape recording).

Kusayina kwemubvunzwi:

Musi:

(Participant's Signature)

(Date)

Mufakazi (Witness):

Musi (Date):

Ini, Natsayi G. Matimba, ndinovimbisa imi mubvunzwi kuti izvo zvese zvamuchanditaurira zvichaongororwa neni chete. Hapana umwe munhu achakwanisa kuziva zita renyu. Izvo zvamunenge manditaurira maererano nekubatsira hama yenyu irikurwara ndizvochete zvichashandiswa muchidzidzo ichi kwete zita renyu kana zvimwewo zvingaite kuti umwe munhu azive kuti ndimi makazvitaure.

Matepu (tapes) nezvinyorwa zvese zvandinenge ndaita pamusoro pekutaura kwedu zvichapiswa pakupera kwefundo iyi.

Kusaina kwomutsvagi:

Musi:

Mufakazi (Witness):

Musi (Date):

IFOMU YOKUVUMELA (CONSENT FORM IN NDEBELE)

Isifundo sokuhlolisisa ngesimo sengqondo lempilakahle kulabo abanika usizo

Ngiyazwisisa okumayelana lesifundo engisicasiselwe ngu Dokotela Matimba. Njalo ngiyazwisisa ukuthi ngikhululekile ukuba ngiyekele ukuqhubeka ngesifundo yiloba kuliphi ibanga esesikulo kungadingakali ukuthi ngicacise ukuthi ngiyekelelani.

Ukusayina kohlanganyelayo:

Usuku:

(Participant's Signature)

(Date)

Njalo ngiyavuma lokuthi ingxoxo le ithetshwe (tape recording).

Ukusayina kohlanganyelayo:

Usuku:

(Participant's Signature)

(Date)

Umfakazi (Witness):

Usuku (Date):

Mina, uNatsayi G. Matimba, ngiyathembisa ukuthi ulwazi lonke ongabele lona, luzahlolisiswa yimi kuphela. Akukho okumayelana lomuntu uqobo okuzavezwa komunye umuntu. Kuphela nje ulwazi lwalowo onika usizo luzakwaziswa njalo lokhu kuzakwenziwa kungaqondiswanga imibono le laloba yiwuphi umhlanganyeli, ngokunjalo

kuqinisa ukungavezwa ibizo lomhlanganyeli. Mina ngokwami ngizatshabalalisa zonke ingwalo lokuyabe kuthetshiwe (tape recordings) ekuqedeni kwalokhu kudingisisa.

Ukusayina kwoMhlolisi:
(Researcher's Signature)

Usuku:
(Date):

Umfakazi (Witness):

Usuku (Date):

DEMOGRAPHIC QUESTIONNAIRE

Age of care-giver:-

Age of care-recipient:-

Gender of care-giver: - F/M

Gender of care-recipient: - F/M

Relationship of care-giver to care-receiver:-

Employment care-giver: - formally employed / unemployed / self-employed

Sero-status of care: - positive / negative / unknown / withheld

Duration of care-giving:-

Patient's Karnofsky score:-

***QUESTION TO BE ASKED TO ELICIT PARTICIPANTS' QUALITATIVE
RESPONSE***

English

How are you finding the experience of looking after your ill relative?

Shona

Muri kuona sei nyaya yekuchengeta hama yenyu iri kurwara?

KARNOFSKY SCORING

- 100-: Normal; No complaints nor evidence of disease. Able to work.
- 90-: Able to carry on normal activity; Minor symptoms. Able to work.
- 80-: Normal activities with effort; some symptoms. Able to work.
- 70 -:Cares for self; unable to carry out normal activity. Independent; not able to work.
- 60-: Disabled; dependent. Requires occasional assistance; cares for most needs.
- 50-: Moderately disabled; dependent. Requires considerable assistance and frequent care.
- 40-: Severely disabled; dependent. Requires special care and assistance.
- 30-: Severely disabled. Hospitalised, death not imminent.
- 20-: Very sick. Active supportive treatment needed.
- 10-: Moribund. Fatal processes are rapidly progressing.

(Adapted from Karnofsky, Abelmann, Craver & Burchenal, 1948)

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