

A TECHNICAL REPORT EXPLORING WHETHER CAREGIVERS OF PEOPLE LIVING WITH HIV/AIDS RECEIVE SUFFICIENT PSYCHO-SOCIAL SUPPORT

A South African Descriptive Study at Community Care Project

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Assignment presented in partial fulfilment of the requirements for the degree of Master
of Philosophy (HIV/AIDS Management) at the University of Stellenbosch



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DECLARATION

I, the undersigned, hereby declare that the work contained in this assignment is my own original work and that I have not previously, in its entirety or in part submitted it at any university for a degree.

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ABSTRACT

“I find that most of the time my heart is sore, and I think a lot, and I feel I need someone to talk to, even if it’s a little kid”.

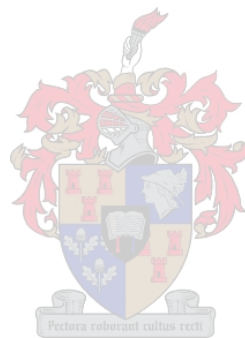
This is one of the desperate voices of one of Community Care Project’s Caregivers. Community Care Project (CCP) provides support for families who are infected and affected by the HIV/AIDS epidemic. The researcher observed that many of the staff, volunteers and carers were experiencing exhaustion, depression and even burn-out as a result of continual caring for people infected by HIV/AIDS. Caring for a Person Living with HIV/AIDS (PLHA) appeared to be a major stressor in the lives of caregivers, which was believed to affect a caregiver’s mental health and his or her ability to cope, as well as a caregiver’s general wellbeing. Thus, the research question was: *“Do CCP caregivers providing care to People living with HIV/AIDS, receive sufficient psycho-social support?”*

The degree of psycho-social support that is presently available to caregivers, as well as whether current support is sufficient for maintained coping by caregivers within the HIV/AIDS context were addressed as an integral part of the research. A phenomenological descriptive survey study design was used to explore the research question.

Forty-two Caregivers participated in this study (population size of 97 possible CCP caregivers). Self-administered questionnaires were completed and two focus groups were conducted to explore the effects that caring for a PLHA had on ones’ coping ability, and whether one had sufficient psycho-social support for maintained coping. Analysis was carried out using manual coding for qualitative data, while the quantitative data was analysed using descriptive statistics.

Results showed CCP caregivers are not receiving sufficient psycho-social support. Results also showed that demographic variables such as age, sex, health of PLHA, type of caregiver, monthly income, number of HIV-related deaths, and number of PLHA’s cared for did not affect a caregivers coping ability. Results showed poor access to and use of emotional support networks. 41 % of caregivers feel they are not currently coping with the stressors of caregiving and 88 % are experiencing one or more symptoms of burnout (the most common being insomnia, with 48% of participants experiencing this symptom).

The study concluded that caregiving has affected physical, mental and spiritual health of caregivers and many expressed that there had been significant decrease in their functioning as a result of their caregiving for PLHA's.



OPSOMMING

“Die meeste van die tyd is ek hartseer, ek tob baie en het ‘n behoefte om met iemand te praat, met enigiemand, selfs ‘n kind”

Dit is die versugting van een van Community Care Project (CCP) se versorgers. CCP ondersteun families wat geïnfekteer en geïffekteer word deur die HIV/VIGS epidemie. Die navorser het waargeneem dat baie personeellede, vrywilligers en versorgers van persone wat met HIV/VIGS geïnfekteer is, die volgende ondervind: uitputting, neerslagtigheid, depressie en selfs uitbranding. Versorging van ‘n Persoon wat met HIV/VIGS leef (PLHA) blyk ‘n beduidende stresfaktor vir die versorger te wees, wat die versorger se geestelike welstand sowel as sy of haar vermoë om sinvol te lewe, beïnvloed. Die versorger se algemene welstand word geïffekteer. Die volgende navorsingsvraag het dis ontstaan: *“Ontvang CCP versorgers van mense wat met HIV/VIGS leef, genoegsame psigo-sosiale ondersteuning?”*

Die stand van psigo-sosiale ondersteuning wat tans beskikbaar is vir versorgers, sowel as die vraag of die huidige ondersteuning voldoende is om te verseker dat die versorgers opgewasse is om die eise te hanteer in die HIV/VIGS konteks, word as integrale deel van die navorsing aangespreek. ‘n Fenomenologiese, beskrywende studie is gebruik om die navorsingsvraag na te vors.

Twee-en-veertig versorgers het aan die opname deelgeneem (uit ‘n populasie van 97 CCP versorgers). Vraelyste is deur die respondente voltooi, terwyl twee fokus groepe gebruik is, om te bepaal wat die uitwerking van die versorging van ‘n PLHA op die versorger se vermoë, asook of daar voldoende psigo-sosiale ondersteuning beskikbaar is om hul eie stres op ‘n volgehoue wyse te kan hanteer. Ontleding is gedoen deur gebruik te maak van hand kodering vir kwalitatiewe inligting terwyl kwantitatiewe data deur middel van beskrywende statistiek ontleed is.

Die resultate toon dat demografiese veranderlikes soos ouderdom, geslag, gesondheid van die PLHA, tipe versorger, maandelike inkomste, aantal HIV/VIGS verwante sterftes en aantal PLHA’s wat versorg word, nie die versorger se vermoë om die situasie te hanteer, affekteer nie. Die resultate bewys dat daar onvoldoende toegang tot en geredelike beskikbaarheid van emosionele ondersteuningsnetwerke is. 41% van die versorgers is van oordeel dat hulle nie opgewasse is teen die spanningsdruk wat

versorging meerbring nie. 88% van die versorgers ervaar een of meer simptome van uitbranding (waarvan die mees algemene simptoom slaaploosheid is met 48% van die deelnemers wat daaraan ly).

Die navorsing kom tot die volgtrekking dat die liggaamlike, verstandelike en geestelike gesondheid van versorgers affekteer word. Verskeie versorgers is van oordeel dat daar 'n beduidende afname in hulle funksionering as 'n direkte gevolg van hulle versorging van PLHA's, ingetree het.



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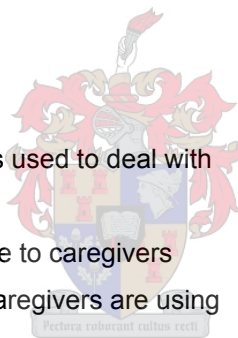
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CHAPTER 1 : INTRODUCTION TO THE STUDY

It appears that many Community Care project Caregivers are experiencing exhaustion, depression and even burn-out, which may be an indication that *caregivers of people living with HIV/AIDS are not receiving sufficient psycho-social support*. Caring for a Person Living with HIV/AIDS (PLHA) appears to be a major stressor in the lives of caregivers, which may affect a caregiver's mental health and his or her ability to cope, as well as a caregiver's general wellbeing. The kind of psycho-social support presently available to caregivers, as well as whether current support is sufficient to maintain functional coping, needed to be researched.

Stressors are “demands made by the internal or external environment that upset balance, thus affecting physical and psychological well-being and requiring action to restore balance” (Lazarus & Cohen, 1977). Mental health includes psychological and psychiatric health. Psychological well-being involves healthy mood, emotions and behaviour. Psychiatric health involves biological, behavioural, and psychological health. (<http://www.hivdepression.org>). Wellbeing is a state of being or doing well in life; happy, healthy, or prosperous condition (Onions, 1973). Coping is “the changing thoughts and behaviours that people use to manage distress (emotion-focused coping) and the problem underlying the distress (problem-focused coping) in the context of a specific stressful encounter or situation” (Moos & Schaefer, cited in Folkman, 2003).

1.1 PURPOSE OF THE STUDY

The context of the research is a Community-based NGO, called Community Care Project (CCP), commonly referred to by the community as Bethany House. CCP forms part of an NGO named Project Gateway. Project Gateway consists of various projects including: New Frontiers School; Pregnancy Crisis Centre; Sunset Shelter; Esther House - a temporary place of safety for abused women and children; Duduza Home - a temporary Foster Care Home and place of safety for children orphaned by HIV/AIDS; BizDev - a micro-enterprise training programme; and Zandla Expressions - a marketing business for micro-enterprise producer groups. CCP is situated in Pietermaritzburg, Kwa-Zulu Natal, South Africa and is managed by a church called Pietermaritzburg Christian Fellowship.

CCP provides support for families who are infected and affected by the HIV/AIDS epidemic. AIDS (Acquired Immune Deficiency Syndrome) is caused by HIV (Human Immunodeficiency Virus). This syndrome is spread by contact between the bodily secretions of the infected person (e.g. blood, semen) and the recipient's blood via a break in their skin or mucus membranes (Webb, 1997). When the virus enters the bloodstream, it attacks the CD-4 T-lymphocytes, which play a vital role in mounting an immune response. DNA from the virus joins with that of the host cell, which results in viral replication. This spreads throughout the body weakening the whole immune system (Yerza et al, 1990). Death of the individual affected occurs from the combined effect of opportunistic infections on his/her debilitated immune system (Kinghorn and Steinberg, 1999).

CCP aims to address the needs of families infected and affected by HIV/AIDS, including poverty alleviation, medical intervention (including wellness promotion), psychosocial support (counselling, debriefing, support groups, bereavement work, memory box, play therapy) and sustainable micro-enterprise projects (e.g. farming, beadwork). CCP also has a training programme, which trains volunteers from the community in HIV/AIDS awareness, home-based care, orphan care, wellness training, basic counselling skills and spiritual support. Some of the trainees continue working with CCP (secondary caregivers) and identify and support families in their communities who are in need of intervention. Presently, CCP is holistically involved in 67 families infected and affected by HIV/AIDS and over 300 orphans and vulnerable children.

Within the CCP context, there are many caregivers who work with people living with HIV/AIDS (children and adults). For the purpose of the study, a caregiver is someone who cares for a Person Living with HIV/AIDS (PLHA) in the community. This study focuses on three types of caregivers, namely: primary, secondary and tertiary caregivers. A primary caregiver is a community member (often a family member) who lives with the PLHA and provides constant care. A secondary caregiver is a caregiver who lives in the same community as the PLHA but does not live in the same house. A secondary caregiver provides support and home-based care to the PLHA and his or her family. A secondary caregiver can also be called a home-based carer. A tertiary caregiver is a staff member at Bethany House (e.g. social workers, occupational therapist, nurses, counsellors, community care workers).

1.2 RESEARCH PROBLEM

As indicated previously many of the caregivers involved at Community Care Project appeared to have experienced exhaustion, depression and burn-out as a result of their involvement in caring for a PLHA.

The research question “***Do CCP caregivers, providing care to people living with HIV/AIDS, receive sufficient psycho-social support?***” seemed to be a very relevant question given the strong emotional content and possible negative emotional affects that caregiving within the HIV/AIDS environment may have on a caregiver. The degree of psycho-social support that is presently available to caregivers, as well as whether current support is sufficient for maintained coping by caregivers within the HIV/AIDS context was addressed as an integral part of the research. Coping is “the changing thoughts and behaviours that people use to manage distress (emotion-based coping) and the problem underlying the distress (problem-faced coping) in the context of a specific stressful encounter or situation” (Moos and Schaefer, cited in Folkman, 2003).

In order to address the research question, the research surveyed the role of caregiving, as well as the extent to which the personal attributes of the caregivers (including the caregivers’ demographic profiles) affected a caregiver’s ability to cope with the stressors of caregiving. The caregivers are quite heterogeneous in terms of their qualifications, age, gender, previous exposure to caring for a PLHA and knowledge of HIV/AIDS. These variables, as well as the caregivers’ particular role of caregiving (that is: primary, secondary or tertiary) were taken into account and carefully controlled in the research.

The following questions were explored to answer the research question:

- Does a caregiver’s particular demographics affect his or her ability to cope? (demographic variables that were investigated included: age; sex; type of caregiver; monthly income; relationship to PLHA; stage of illness of PLHA; number of PLHA’s a caregiver cares for; number of HIV related-deaths)
- Is there a relationship between the use of support networks and his or her ability to cope?
- Is there a relationship between use of coping mechanisms and his or her ability to cope?

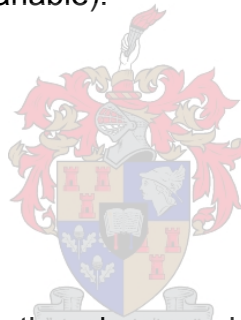
- Is there a relationship between the caregivers' current stressors and his or her ability to cope?
- Is there a relationship between current stressors and signs of burnout?

The Null hypothesis to investigate the research question was: *Looking after PLHA'S does not effect one's coping ability.*

The scientific hypothesis was: *Caregivers of PLHA'S have a poor coping ability.*

With reference to the above hypotheses, it was argued that age, gender, type of caregiver, relationship to PLHA, monthly income, stage of illness of PLHA, number of PLHA's the caregiver provided care for, number of HIV-related deaths the caregiver had experienced, access and use of support networks, use of coping mechanisms and type of current stressors (independent variables) may have a significant effect on the coping ability of caregivers (dependent variable).

1.3 RESEARCH OBJECTIVES



1.3.1 Aim

With reference to the above mentioned research question, the research intended to explore the psycho-social impact that looking after a person with HIV/AIDS has on one's ability to cope and whether existing support networks are sufficient for maintaining one's coping ability.

1.3.2 Objectives

In view of the above stated research problem and question, the following objectives were set for the study:

1. *To determine the demographic profile of caregivers including:*
 - Gender of caregiver
 - Age of caregiver
 - Is the caregiver a primary caregiver, secondary caregiver or tertiary caregiver?
 - Number of HIV-positive/ sick children they care for

- Number of HIV-positive/ sick adults they care for
- Caregiver's relationship to the Person Living with HIV/AIDS (e.g. grandmother)
- Stage of HIV/AIDS of the PLHA. For example, HIV-positive but healthy, HIV-positive with occasional illness, HIV-positive with frequent illnesses or bed-ridden.
- Number of HIV related deaths the carer has had to cope with
- Caregiver's knowledge of HIV/AIDS
- Monthly household income

The demographic profile of caregivers was included in order to research the role and significance of specific demographic variables on coping ability, as well as the need for psycho-social support.

2. *Determine what current psycho-social support is available to caregivers.*

The research explored what local psycho-social support networks are accessible and used by caregivers, such as church, friendships, support groups, HIV/AIDS awareness groups, mental health department, NGO'S. This was to determine the individual psycho-social needs of each caregiver and to help promote psycho-social service delivery.

3. *Determine caregivers current coping ability, with regards to the stress of caregiving*

It was assumed that caring for a PLHA is a stressor in a caregiver's life. Thus it was important to research if and how this stressor has negatively affected a caregiver's coping ability.

Thus one can see from the research problem and research objectives highlighted in chapter 1, that a comprehensive literature review needed to be done in order to explore how caregiving for a PLHA may affect a caregivers coping ability.

CHAPTER 2 : LITERATURE STUDY

The following literature review explores current research about how caregiving for a PLHA affects a caregivers coping ability.

“People with HIV and those close to them are subject to numerous stressors that can impact their mental health. Among these stressors are fear and anxiety following the initial disclosure of HIV seropositivity, stressful and confusing medical treatment regimens, the prospect of serious medical problems, and the sadness and grief associated with having a foreshortened future” (<http://www.hivdepression.org>, 2004). These stressors have the potential to affect a caregiver’s mental health and ability to cope.

If a caregiver is not able to use effective coping mechanisms to deal positively with these stressors, “Burn-out” may result. Burnout or role-stress may be defined as “a syndrome of physical and emotional exhaustion, involving the development of a negative self-concept, negative job attitudes, and loss of concern and feelings for clients” (Pines & Maslach, 1978, p.233). Schaufeli & Enzmann, cited in Strommel & Rothman (2003), state that there are another three symptoms to burnout, namely: distress, decreased motivation and dysfunctional attitudes and behaviours at work. As mentioned in the research problem, many carers of CCP seem to present with some of these symptoms.

Burnout is when a person displays mental and physical exhaustion (compassion fatigue) as a result of caring for the demands of others; leading to depersonalisation of the person they are caring for as they emotionally detach themselves; and ultimately decreased productivity and reduced personal accomplishment if not dealt with (Maslach, 1983; Ramirez, Graham, Richards, Cull and Gregory; 1995).

The emotional strain of caring can also lead to physical and emotional complications such: as insomnia, chronic fatigue, tiredness, feeling run down, increased susceptibility to illness, depression, anxiety, poor appetite, lost hope, decreased motivation, feelings of failure, chronic pain such as backache, nightmares and absenteeism (Maslach, 1983; Schaufeli and Enzmann, cited in Storm and Rothman,2003).

Poverty, the stigma around HIV/AIDS resulting in discrimination and the increase of many orphans and vulnerable children (as a result of many HIV-related deaths) have exacerbated the risk of burnout for caregivers in developing countries, like South Africa (Defilippi, cited in Cameron and Uys, 2003). Thus in the context of CCP, caregivers are at risk of burnout.

If “burnout” is not controlled it may lead to depression, which will affect the caregivers’ ability to provide optimal care and support to the PLHA. Depression in the context of HIV/AIDS is caused by many factors including: “feelings of lack of control over one’s fate, changes in a person’s self image - from being healthy to being sick, worry over the implications of the illness on personal relationships and circumstances, exposure to stigma and possible resulting abuse, and the perceived and real risks of disclosure” (Wright and Coyle, 1996). One needs to look at how one can control the effects of burnout and depression in HIV/AIDS caregivers.

“Stress is omnipresent in our lives, stress can be harmful to life...these harmful effects can be avoided or reduced if we cope well.” (Folkman, 2003) So what helps an individual to cope well?

A study conducted by Naidoo and Le Roux (2003) asked the question: Where do those who are better able to cope, derive their strength and resilience from? They researched the participants’ sense of coherence. Sense of coherence, which forms a crucial part of salutogenesis (developed by Antonovsky) is “the pervasive and enduring feeling of confidence that the internal and external environments are predictable and that things will work out as can be reasonably expected” (Antonovsky, cited in De Beer and Korf, 2004). Sense of coherence is the ability to deal with situations in a structured manner in terms of:

- Comprehensibility: Is the problem or stressor ordered, explainable and predictable?
- Manageability: Does one have the necessary resources to deal with the problem or stressor?
- Meaningfulness: Is the stressor or problem worth investing and engaging in? (Strumpfer and Mlonzi, 2001; Antonovsky, 1979; Cooper, Kalimo & El-Batawi,

1987; Flannery & Flannery, 1990; Flannery & Flannery, 1990; Strumpfer, 1995; Levert, Lucas & Ortlepp, 2000).

Naidoo and Leroux (2003) found that there was a significant inverse relationship between 'stress' and 'sense of coherence'. They concluded that 'sense of coherence' is a conditioning variable that mediates the feeling of stress. Virtue & Jansen (1996) also found statistically significant correlations between sense of coherence and general well-being. Antonovsky's (1979) theory states that people with a high 'sense of coherence' will be able to deal with stressful situations better than people who have a low 'sense of coherence'. Thus research bears this in mind when looking at the caregiver's coping ability.

Breed (1997) shows that a 'sense of coherence' has been found to correlate negatively with anxiety, depression and physical symptoms and positively with hardiness and locus of control. There is a negative correlation between 'sense of coherence' and emotional exhaustion (Rothmann, Malan and Rothmann, 2001). A sense of coherence and resilience in CCP caregivers thus seems essential and should be considered as important prerequisites in selection and training of secondary and tertiary caregivers.

Strumpfer (2003) believes that sense of coherence may assist in warding off burnout, but this has not been proved scientifically.

The Salutogenesis Model is therefore helpful in looking at why individuals cope.

Strumpfer (1995) identified the following six constructs as core dimensions to coping or being a salutogenic individual:

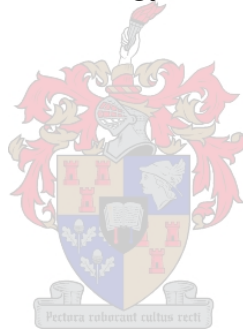
1. *Sense of coherence* (see earlier definition).
2. *Locus of control* – the belief that behaviour has a direct impact on life events and that one's own actions can make a difference in changing potentially stressful situations as opposed to being at the mercy of others (De Beer and Korf, 2004).
3. *Self-efficacy* – the ability to initiate coping behaviour by using cognitive, social and behavioural dimensions (De Beer and Korf, 2004).
4. *Hardiness* – is the ability to use many strategies to cope with a potential stressor. It involves a commitment to deal with the stressor proactively and having a positive

outlook that a stressor is a challenge that can help one grow, instead of a stressor being viewed as a threat (Kobasa, cited in De Beer and Korf, 2004).

5. *Potency* – the ability to control one’s emotions whilst under stress (De Beer and Korf, 2004).
6. *Learned resourcefulness* – is being able to draw from past experience of coping with stressful events. It is not dependent on the personality of an individual (De Beer and Korf, 2004).

These dimensions of coping were researched and used to explain why certain individuals cope better than others, when undergoing the same stressor. Salutogenesis needs to be developed in all HIV/AIDS caregivers to develop coping ability (see recommendations).

This chapter highlighted how caring for a PLHA may effect one’s coping ability. The following chapter will look at the methodology used to explore the research question.



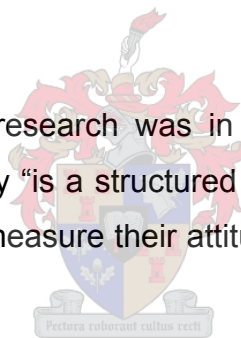
CHAPTER 3 : METHODOLOGY

The aim and objectives of the study (see chapter 1) required a combination of qualitative and quantitative methodologies. The combination of using qualitative and quantitative research methods, through triangulation, aims at compensating for the weaknesses of each method. “Triangulation increases scope, depth and consistency in methodological proceedings” (Flick, 1998, p.230). Thus for this research a combination of quantitative and qualitative research methodologies were used.

The quantitative method was chosen as most appropriate in obtaining baseline information of demographics and information about psycho-social support networks and current coping ability of the caregivers. The qualitative method was seen as necessary to enrich these findings, and elicit further information not otherwise attainable through quantitative measures.

Quantitative Component

The quantitative aspect to this research was in the form of a survey, administered through a questionnaire. A survey “is a structured set of questions or statements given to a group of people in order to measure their attitudes, beliefs, values or tendencies to act” (Goodwin, 2002, p.398).



Qualitative method

Qualitative research is an interpretive, multi-method approach that investigates people in their natural environment” (Denzin and Lincoln, cited in Christenson, 2004; p.51). A descriptive phenomenological approach is one of these non-experimental methods, and begins with a description of the experience. In this case asking: what is the experience of being a caregiver? A description of an experience (or narrative analysis) is extracted through an in-depth interview or focus group (Camic, Rhodes and Yardley; Coolican, 1999). In this study, narrative focus groups were appropriate to qualify the research question: *Do caregivers of PLHA's receive sufficient psycho-social support?* A Focus group is a technique that is helpful to explore a theme and set of topics in detail with participants. Focus groups aim to “encourage, by means of the interactional dynamics operating in the group, free discussion of shared meanings (including contestation and debate) of a kind not ordinarily attainable in a one-to-one interview study” (Camic et al., 2003; p.141).

3.1 RESEARCH DESIGN

The research design is a qualitative study with a quantitative component, namely: a phenomenological descriptive survey. This is a viable research methodology (Walker, 1996; cited in Goodwin, 2002)

3.2 SAMPLING

It was impossible to study the entire population of caregivers at CCP, owing to availability of caregivers. A convenient sample of participants who meet the general requirements of the study and who were available at the time of the research formed the sample for the study (Coolican, 1999; Goodwin, 2002). Thus in this study, the target population of 97 CCP caregivers (consisting of 67 primary caregivers, eight secondary caregivers and 22 tertiary caregivers) were invited to a community forum where details of the research and an opportunity to be part of the study was given. 42 participants attended the community forum. All 42 consented to be part of the study and completed the questionnaires.

Following the questionnaire a random sample of two groups of three primary caregivers, three secondary caregivers and three tertiary caregivers was taken to participate in qualitative focus groups for further narrative research.

3.3 MEASUREMENT INSTRUMENTS

The method of data collection of this study was by questioning, and included two measurement tools, namely:

3.3.1 A questionnaire

This was used to determine the demographics of the caregivers', their current ability to cope with the stressors of caregiving and their current psycho-social support networks. The questionnaire consisted of open ended questions (qualitative data) and close ended questions (quantitative data) [see Appendix 1]. Christenson (2004) suggests that a questionnaire not be too long, otherwise participants will lose interest, so the

questionnaire was three pages long and took approximately 15 minutes to complete. This questionnaire used Antovosky's *Orientation to Life Questionnaire* (1979) Maslach's Burnout Inventory (1996) and Goldberg's *General Health Questionnaire* (1972, 1978, 1988) to develop questions about stress, burnout, depression and coping ability.

3.3.2 Focus groups

Two focus groups were compiled, consisting of a random sample of three primary caregivers, three secondary caregivers and three tertiary caregivers in each group. Focus group sessions took place one week after the questionnaire was administered. Eight participants attended the first focus group and seven attended the second focus group. The focus group sessions lasted approximately one and a half hours and the narratives of participants were recorded. Focus groups were guided by the theme: "*My experience of providing care to a PLHA*". Topics such as the following were covered:

1. What are caregivers' day-to-day experiences of caregiving? (positive and negative)
2. What are caregivers' current stressors?
3. What are the effects of caregiving on caregivers' health? (symptoms of burnout)
4. Are caregivers coping with the stress of caregiving? (Reasons for current coping ability)
5. How do caregivers deal with stress? (coping mechanisms including 'sense of coherence')
6. What would assist caregivers to cope better?
7. How has caregiving effected caregivers' functioning in their roles (for example: mother, friend, husband, colleague) since caring for a PLHA?

The responses of the participants were recorded onto audiocassette and then transcribed.

3.4 DATA GATHERING

In order to accommodate more participants, the questionnaires, which were drawn up in English, were also translated into isiZulu, allowing participants to answer it in their home language where necessary. The questionnaires were worded as simply as possible to ensure ease of translation into Zulu, and therefore aid in participant comprehension. The questionnaire was individually translated into Zulu by two different translators, who then collaborated to arrive at the final translation.

The questionnaire was piloted with the staff at CCP, using three participants (one English and two isiZulu) who had consented to the study. Following the pilot study, no alterations were made to the questionnaire, as the pilot study showed that the existing format was easily understood and user-friendly. The data collected during the pilot study was included in the results.

The researcher was known to all of the caregivers. The researcher visited the target population prior to piloting the study to introduce the proposed study, questionnaires and focus groups. All caregivers were then invited to a community forum, where the needs of caregivers were discussed and the proposed research explained .

The purpose and procedure of the research was explained to all the potential participants in English and IsiZulu. Opportunity was given to ask questions for clarification. Potential participants were then given the option to take part in the study, and on confirmation of their inclusion, were requested to sign a consent form. The caregiver's who signed the consent form and agreed to be part of the study were then invited to complete a written questionnaire in the language of their choice. Two research assistants were available to help illiterate caregivers to communicate. The researcher was available to clarify any questions or queries. In order to prevent researcher bias, research assistants were given a standardised procedure to administer the questionnaire to illiterate caregivers. The standard procedure was as follows:

1. Explain purpose of study and emphasise anonymity and confidentiality
2. Ask caregiver if he or she would like to take part in the study
3. If yes, ask caregiver to complete consent form
4. Ask participant if they want to answer in English or Zulu

5. Allot a number to the participant.
6. Place name with corresponding number in register in the event of needing clarification for questions. Explain that this information will be confidential and name is necessary for clarification only.
7. Explain that if there are any queries regarding the questionnaires, the participants can make use of the researcher or research assistant for clarification.
8. Participants to complete questionnaire. Researcher and assistants to clarify only if participant asked specifically about question. Research assistants to help illiterate participants by asking questions verbally and recording on questionnaire form.

A random sample of three primary, three secondary and three tertiary caregivers for each focus group was drawn. The random sample was chosen from those caregivers who had signed consent forms and agreed to be part of study. Chosen participants were given dates and times for focus groups.

In each focus group, group norms (for example, confidentiality, cell-phones to be switched off, respect for one another, listening when others are talking) were established before the discussions commenced. The researcher guided participants through eight semi-structured questions. Participants were given pen and paper to formulate their thoughts if necessary. Discussion and responses from the focus groups were recorded onto audio-cassette and then transcribed, translated and analysed into codes, categories and themes.

Coding was used in analysing the qualitative data, as coding reduces the information gathered from the narratives to something that is meaningful. It helps to filter information that answers the research question from irrelevant data (Camic et al; 2003). A category combines all similar statements from the transcripts. Several similar categories are then combined to obtain a theme. (Camic et al, 2003).

One translator was used to transcribe and translate the responses from the tape and to ensure consistency of translation.

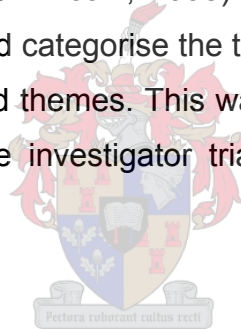
3.5 DATA ANALYSIS

3.5.1 Quantitative Data

Data obtained were processed and displayed in terms of frequencies, percentages and relationship to the research question. Statistical significance between key variables being compared were further determined, but the relatively small sample size placed certain restrictions on the extent of statistical analysis.

3.5.2 Qualitative Data

The questions representing the qualitative component of the study were transcribed and translated into English. The transcripts were analysed by means of thematic coding in order to develop categories and themes, so as to structure and formulate the information obtained (Denzin and Lincoln, 1998). One researcher and two assistants were used to individually code and categorise the transcripts before collectively deciding on the final codes, categories and themes. This was to ensure comprehensive analysis of the transcripts and to provide investigator triangulation, which reduces individual researcher bias.



3.6 ENSURING RIGOUR

Further measures of ensuring rigor were implemented by an external, objective person who did not know the aims of the research. These measures traced and confirmed the themes and categories extracted from the qualitative data. Rigour (or good practise) was insured by triangulation, which is getting “more than one perspective on the same situation, events or person” (Coolican, 1999, p.165).

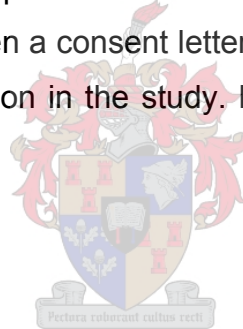
Standardised procedures gave the person conducting the focus groups or questionnaire the exact instructions on how to conduct the questionnaire or focus group, treating all participants in the same way and reducing bias possibility of extraneous variables affecting the results (Coolican, 1999). Research assistants who are coding data were unaware of research aims in order to avoid researcher bias (Coolican, 1999). Using a computer programme also reduced bias.

There are many disadvantages to using a standardised test (for example, the Maslach Burnout Inventory), as standardised tests do not gather narrative and personally meaningful data that one can gather from qualitative methods (Coolican, 1999). Participants may also feel nervous doing a standardised test as they might be afraid of failure and being evaluated. There is also room for participants to misinterpret the questions on the standardised test, whereas in a focus group they can ask for clarification (Coolican, 1999).

3.7 ETHICAL AND LEGAL CONSIDERATIONS

3.7.1 Obtaining consent

Before administering the study, informed consent was obtained from the relevant participants (Coolican, 1999). The researcher introduced herself to the caregivers and explained the procedure and requirements of the study, to insure informed consent. Thereafter the caregiver was given a consent letter (in their choice of English or Zulu) to sign confirming his/her participation in the study. Details of the study were outlined on the consent letter.



3.7.2 Confidentiality

Confidentiality (particularly with respect to HIV/AIDS status) was an important aspect of this study. The names of the participants were replaced with numbers on the relevant documents and audiocassette responses, to ensure the participants' anonymity (Coolican, 1999). The verbal responses of the focus groups were captured in a private room in the presence of one researcher, to guarantee confidentiality. The caregivers were assured, prior to their involvement, that they would not be referred to personally in the study, and that any information obtained from them would only be used in connection with research about developing better psycho-social support networks for caregivers.

In chapter three the Methodology of the research was highlighted in terms of research design, sampling, measuring instruments, data gathering, data analysis, rigor, ethical and legal considerations. The following chapter discusses and depicts the results of the study.

CHAPTER 4 : RESULTS

Results are depicted according to the three objectives of the study. From the study population of 97 caregivers who are involved at CCP, 42 people signed consent letters and participated in the questionnaire. 15 of these participants formed part of two focus groups. Their discussions in the focus groups were analysed by coding, categorising and theming their responses.

4.1 DEMOGRAPHIC BACKGROUND OF CAREGIVERS (Objective 1)

The following demographics of CCP caregivers were captured by using a self-administered survey questionnaire.

4.1.1 Age and sex of caregivers

Of the 42 caregivers who consented to take part in the study, 36 were female, five were male and one did not give their gender. The majority of caregivers were between 31 and 50 years of age (30 % of caregivers). 25% of caregivers were between 20 and 30 years; 20 % between 41 and 50 years; 12.5% between 51 and 60 years and 12,5 % between 61 and 70 years. The mean age of caregivers was 40 years.

This is consistent with Folkman and Chesney (1994) who show that most caregivers of PLHA's are between the ages of twenty and forty. Chi-squared test results indicated no significant relationship between the age nor the sex of caregiver and whether a caregiver is coping. (p -value = 0,253 and 0, 428 respectively).

4.1.2 Type of caregiver

The following graph shows what role the caregiver fulfils in caring for a PLHA, for example a primary caregiver:

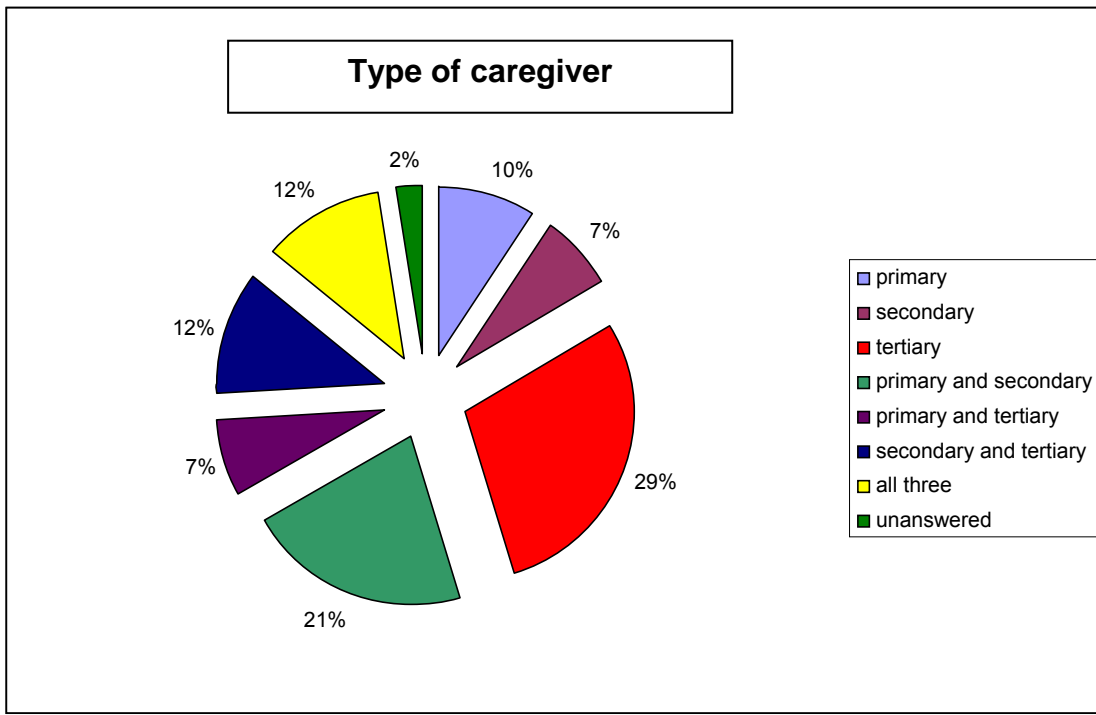


Figure 1: Type of caregiver

As one can see from Figure 1, the majority of caregivers are tertiary caregivers (29%) with the second biggest category being caregivers who are primary and secondary caregivers. A significant percentage (12%) fulfilled the role of primary, secondary and tertiary caregiver. Chi-squared test results indicated no significant relationship between the type of caregiver and whether caregiver was coping or not. (p-value = 0,882)

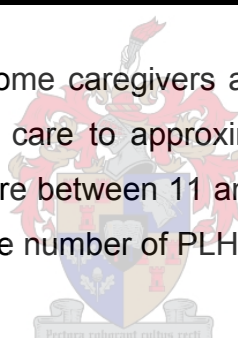
4.1.3 Number of PLHA's being cared for

The following table depicts the number of children PLHA's and the number of adult PLHA's a caregiver is caring for.

Table 1: Number of child and Adult PLHA's a caregiver cares for

NO OF CHILDREN			NO OF ADULTS		
	FREQUENCY	PERCENT		FREQUENCY	PERCENT
0-2	24	57.10	0-2	25	59.50
3-4	11	26.20	3-4	1	2.40
5-7	3	7.10	5-7	2	4.80
8-10	1	2.40	8-10	2	4.80
11-20	1	2.40	11-20	8	19.00
+ - 150	1	2.40	MANY	2	4.80
NO ANSWER	1	2.40	+ - 150	1	2.40
TOTAL	42	100.00	NO ANSWER	1	2.40
			TOTAL	42	100.00

As one can see from Table 1, some caregivers are caring for a significant number of PLHA's. One caregiver provides care to approximately 150 adults and 150 children; whilst eight caregivers provide care between 11 and 20 children PLHA'S. There was no statistical significance between the number of PLHA's a caregiver cared for and whether they were coping or not.



4.1.4 Relationship to PLHA

The following graph shows the relationship of the caregiver to the PLHA:

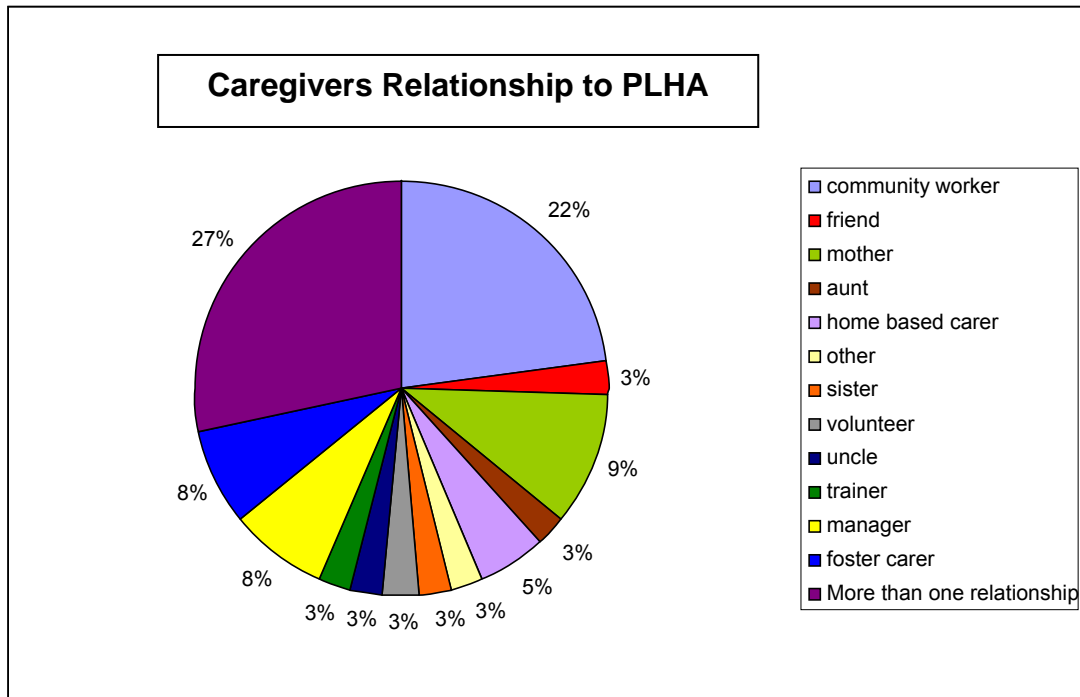


Figure 2: Relationship to PLHA

From Figure 2 it is clear that the majority of caregivers have more than one relationship with a PLHA, for example grandmother and colleague. The second biggest category was community workers (22%) who are working alongside the PLHA in their community. There was no significant correlation between relationship to PLHA and coping ability ($p=0.572$).

4.1.5 Health of PLHA

The following graph shows the health of the PLHA's being cared for. Health is divided into stages of HIV/AIDS: stage 1 is HIV positive but healthy; stage 2 is HIV positive with occasional illness; stage 3 is HIV positive with frequent illness; stage 4 is HIV positive and bedridden needing 24 hour care. As one can see from the graph, most PLHA's are in stages 1 and 2 of HIV/AIDS (being healthy or having occasional illness). Focus groups explained this data to be a result of access to anti-retrovirals and prophylaxis such as bactrim, which ensures that PLHA's stay healthier for longer. One participant expressed: "Very few people are dying now because they are on ARV's".

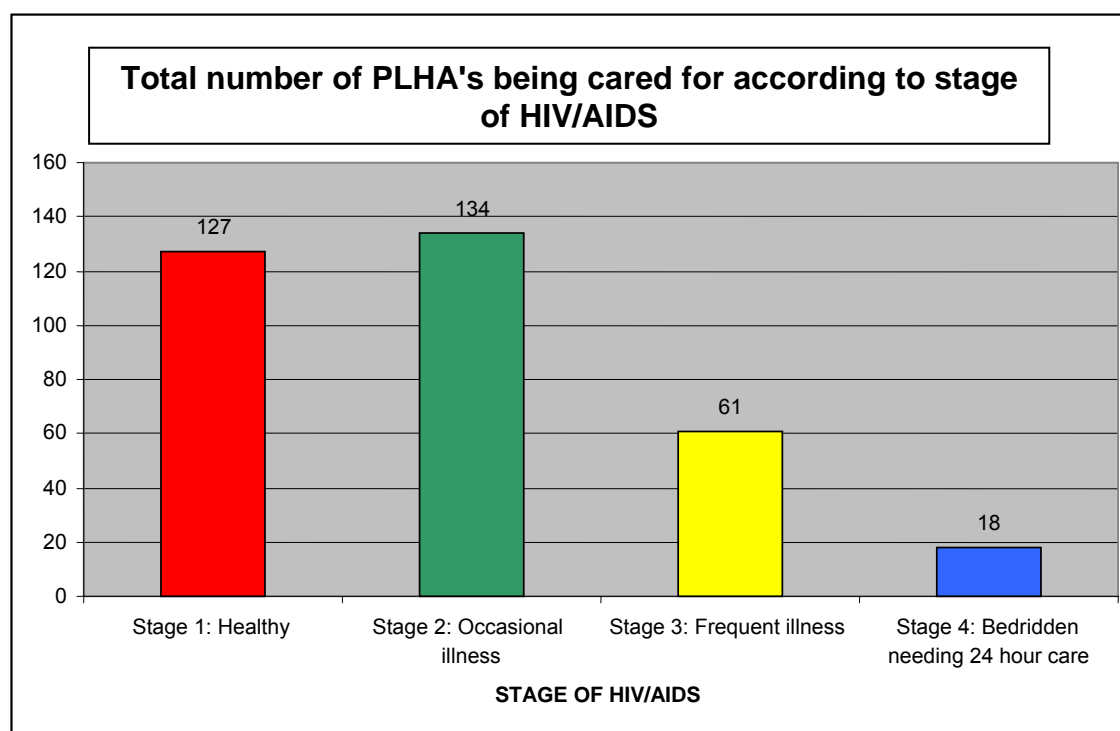


Figure 3: Health of PLHA

However, the health of the PLHA can still be a significant stressor in the lives of caregivers. The caregiver of a PLHA may have to help the person through many stressful medical conditions. Some of these may include:

- Generalised lymphadenopathy
- Chronic/recurrent diarrhoea
- Oral candidiasis
- Pulmonary disease (e.g. TB, Pneumonia)
- Frequent bacterial infections (sepsis, UTI, meningitis etc) (Clayton, 1993)

This substantial list indicates that caregivers need to constantly monitor the PLHA's medical condition, as well as ensure that the person is compliant with medication. This is an added burden and responsibility, preventing them from continuing with their own lives and attending to their own needs. This is likely to negatively affect the caregiver's coping ability. However, Chi-squared test results showed that no statistical significance was found between the stage of illness of PLHA and whether a caregiver is coping or not.

4.1.6 Number of HIV/AIDS-related deaths

The following table shows the number of HIV/AIDS related deaths caregivers have had to deal with:

Table 2: Number of HIV/AIDS-related deaths

NO OF DEATHS	FREQUENCY	PERCENT
0-2	15	35.7
3-5	7	16.7
6-8	5	11.9
9-11	2	4.8
12-20	5	11.9
MANY	7	16.7
+ - 400	1	2.4
TOTAL	42	100.00

One can see from these shocking statistics that caregivers have to deal with significant numbers of HIV related deaths. One caregiver in a management position has had to cope with approximately 400 HIV-related deaths, whilst five caregivers have had to deal with between 12 and twenty HIV/AIDS related deaths. Seven caregivers had experienced too many deaths to be able to count. Chi-squared test results indicate no significant relationship between the number of HIV related deaths and whether a caregiver is coping or not. (p -value = 0,557). Uys (2002) found that many caregivers and PLHA'S attending her support group were struggling with unresolved bereavement from previous HIV-related deaths in their families. So this may affect the coping ability of caregivers, although there is no significant relationship.

4.1.6 Knowledge of HIV/AIDS

The following table is taken from question 11 of the questionnaire, an open-ended qualitative question and explores caregivers knowledge of HIV/AIDS and how to protect themselves from infection. The answers are displayed as categories and themes:

Table 3: Themes and categories of caregivers’ understanding of HIV/AIDS and how to protect themselves from infection or reinfection (question 11 of questionnaire).

THEMES	CATEGORIES
HIV is a deadly disease	<ul style="list-style-type: none"> • It’s a serious killing disease • Incurable
HIV attacks the body	<ul style="list-style-type: none"> • How it effects the body • Modes of transmission- Blood, sex, bodily fluids
HIV affects society	<ul style="list-style-type: none"> • Orphans • Community • Poverty • Crime
Living a healthy lifestyle can control the effect of HIV/AIDS	<ul style="list-style-type: none"> • Healthy lifestyle • Protection is your own responsibility • Self motivation • HIV is not a death sentence
Good infection control prevents the spread of HIV	<ul style="list-style-type: none"> • Infection control
Be careful...safe sex practises help reduce the risk of HIV transmission	<ul style="list-style-type: none"> • Safe sex practises • Abstain • Be faithful • Condomise

This table shows that caregivers generally have a good knowledge about HIV and how to protect themselves from infection. “It’s a very bad virus...very infectious” is one of the responses given by the participants. One can see that caregivers have experienced the seriousness of HIV/AIDS.

4.1.8 Monthly Income

One of the significant stressors experienced by caregivers is financial pressure, with financial burdens being the lead stressor noted by caregivers (60% of caregivers- See Figure 7, p.39). The following table shows the average monthly income of caregivers. One can see that many caregivers receive less than R1000 per month and are still providing care to many PLHA's, resulting in significant stress. However, no significant relationship was found between monthly income and whether caregiver is coping or not. (p-value = 0,193)

Table 4: Monthly income of caregivers

		Frequency	Percent
Valid	R0-R200	3	7.1
	R201-R500	6	14.3
	R501-R1000	6	14.3
	R1001-R2000	8	19.0
	R2001-R5000	6	14.3
	R5001-R10000	6	14.3
	OVER R10000	4	9.5
	Total	39	92.9
Missing	System	3	7.1
Total		42	100.0

4.2 CURRENT PSYCHO-SOCIAL SUPPORT

4.2.1 Coping Mechanisms

According to question 13 of the questionnaire, caregivers use the following coping mechanisms to relieve stress:

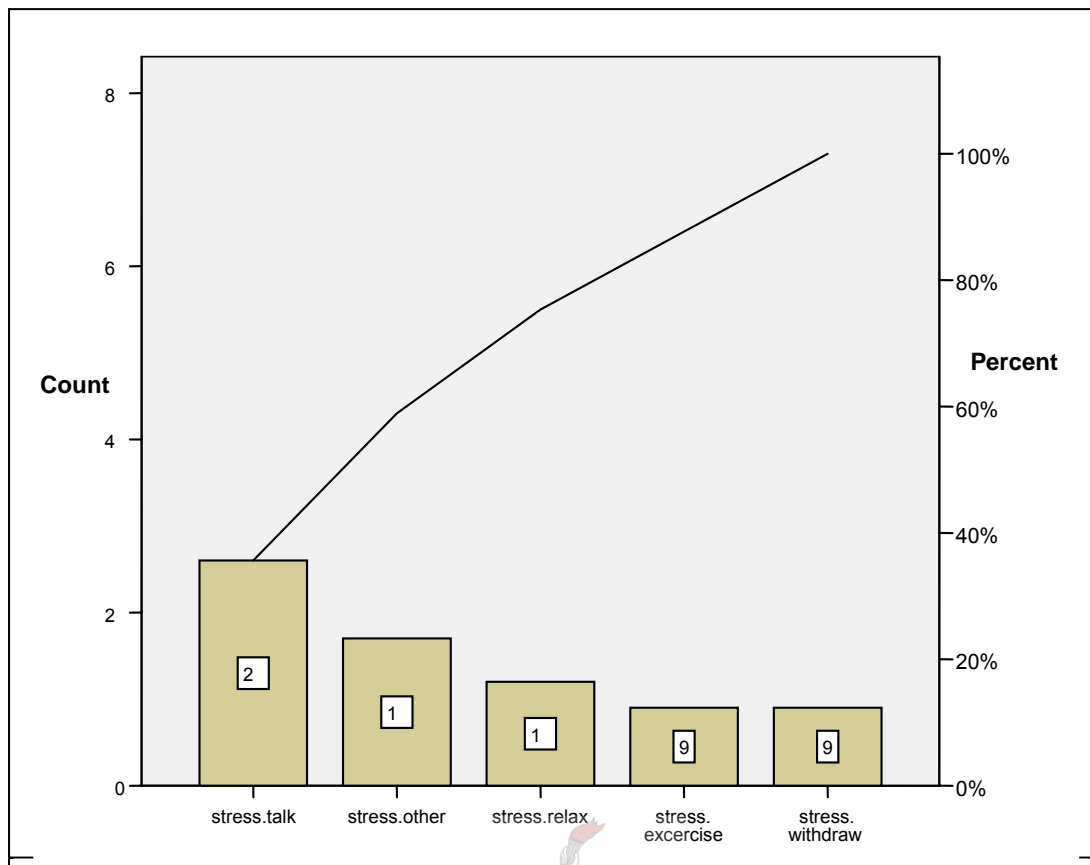


Figure 4: Type of coping mechanisms used to deal with stress

As one can see the most common coping mechanism is talking to someone (62% of caregivers). Very few caregivers use withdrawing or exercise as a coping mechanism. The “other” category consisted on coping mechanisms such as: swimming, having a hot bath, praying and singing; working in the garden; being counselled by a priest; reading, slowing down, watching TV and talking to dogs.

Through the administration of a One way ANOVA test of variance, a significant relationship was found between using the coping mechanism of withdrawing and crying and a caregiver being able to cope with the stress of caregiving. (p -value = 0,077) No other significant relationships were found between using coping mechanisms and coping.

Coping mechanisms caregivers use to combat stress were further elaborated on in the focus groups. The following themes and categories show some of the other coping mechanisms caregivers use to combat stress (taken from focus group responses):

Table 5: Themes and categories of what caregivers do to relieve stress (question 5 of focus groups)

THEME	CATEGORY
Talk about my stressors	<ul style="list-style-type: none"> • Talk to someone • Talk to God • Use supervision
Spiritual Input	<ul style="list-style-type: none"> • Pray • Go to Church • Talk to God
I do something passive	<ul style="list-style-type: none"> • I Listen to music • I rest • I sleep • I relax
I do something active	<ul style="list-style-type: none"> • I play sport • I go out and have fun • I do something that I enjoy • I try to be spontaneous • I do housework
I do something that makes me feel good	<ul style="list-style-type: none"> • I eat nice food to feel better
I need solitude	<ul style="list-style-type: none"> • I want to be alone

Information gained from the focus groups thus supports the questionnaire data and it appears that many caregivers use talking to someone to help relieve stress. Active coping mechanisms such as playing sport, doing housework and having fun are also common coping strategies.

Leisure appears to provide opportunities for effectively coping with stressors. Leisure pursuits have inherent properties of freedom of choice, a sense of control, and intrinsic motivation, which help people to maintain their health despite being exposed to stressful circumstances (Coleman and Iso-Ahola, cited in De Beer and Korf, 2004). Leisure helps someone to momentarily escape from stressful events or painful experiences (Driver, Tinsley, and Manfredo, 1991; Sharp and Mannell, 1996). Thus one can see that these

leisure pursuits such as playing music, sport and praying are effective coping mechanisms in dealing with stress.

4.2.2 Access to and use of support networks

Caregiver's have access to support networks as depicted in Figure 5.

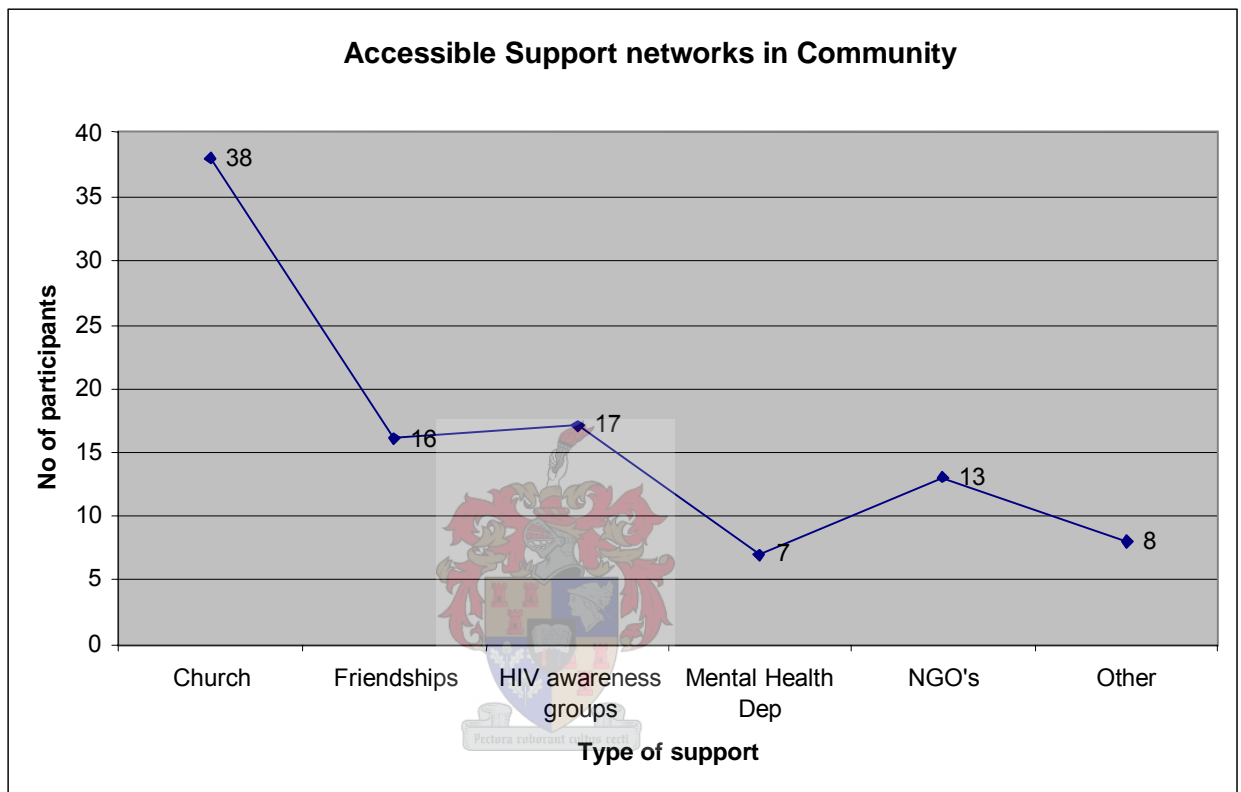


Figure 5 : Support networks accessible to caregivers

There is a big discrepancy between what support networks caregivers have access to and what they are currently making use of. The church appears to be the most accessible support network with 90 % of caregivers having access to a church. Although the church is accessible to most caregivers, many do not use the church as a support network. Only 23 out of the 38 caregivers, who have access to a church, use the church for support (55 % of caregivers). One explanation for this is that some caregivers in the focus groups said that they did not trust people in the church or their friends because of the stigma of HIV/AIDS.

The following graph depicts what support networks caregiver's are currently using.

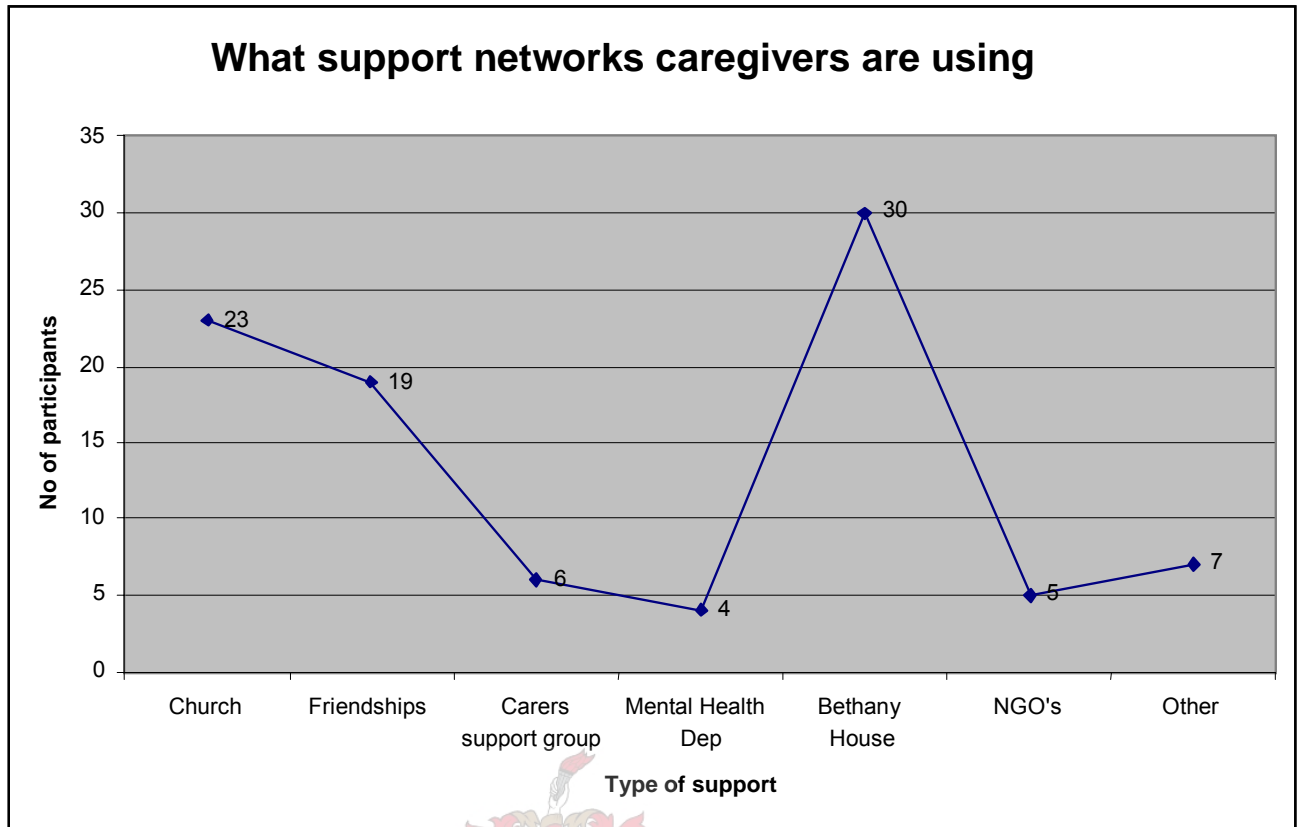


Figure 6: Current support networks caregivers are using

As one can see an overwhelming majority use CCP (Bethany House) as a primary support network (71 % of all caregivers). This may explain why many tertiary caregivers are experiencing signs of burnout and are not coping, as primary and secondary caregivers are looking to them for their primary means of emotional support. 10 out of 12 tertiary caregivers are not coping (83%) with the stressors of caregiving.

4.3 CAREGIVER'S CURRENT COPING ABILITY

One of the most important objectives of this research was to ascertain whether caregivers are coping or not and whether their current psycho-social support systems are sufficient for maintained coping ability.

4.3.1 Caregivers experience of Caregiving

The following table highlights focus group discussion by caregivers about what their day-to-day lived experience as a caregiver is like. Positive and negative experiences were shared.

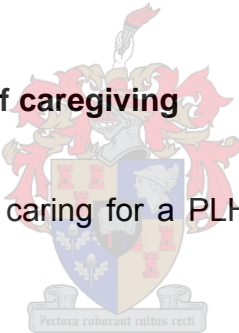
Table 6: Themes and categories of the caregivers' experience of caregiving (question's 1 and 8 of focus groups)

THEMES	CATEGORIES
There are many different types of work	<ul style="list-style-type: none"> • Working With Children • Wellness • Working With Schools • Home-based Care • Voluntary counselling and testing • Training
I don't live in the community	<ul style="list-style-type: none"> • I don't live in the community
I advocate for the Rights of orphans	<ul style="list-style-type: none"> • Orphans have rights
There are negative aspects to caregiving	<ul style="list-style-type: none"> • People die • Unpredictable • Emotionally draining • Lack of knowledge • Caregiving is a difficult task • Clients don't listen • Poor medical care at hospitals • Stigma • I see many sick people
There are positive aspects to caregiving	<ul style="list-style-type: none"> • Empathy for the poor conditions in the community • I have learnt new skills • Seeing people go from crisis to having hope • Seeing the achievements of clients • Impartation of love • Having an opportunity to share the gospel • Having positive new experiences • Seeing a change in negative situations • It gave me confidence • ARV's make our load lighter • Seeing positive behaviour change • Children receiving ARV's and hope
Qualities Of A Caregiver	<ul style="list-style-type: none"> • Caregivers must be brave • Caregivers must bring hope • Caregivers must believe in themselves

It is clear from this table that there are many different experiences to caregiving, some being positive and many being negative. All of these experiences may influence whether a caregiver is coping or not. Caregivers are struggling in the community. The following responses from caregivers depict how hard caregiving is: “Some of them die and you get stressed” ; “Just seeing very very sick children is just hard emotionally” and “When you’re going into situations you sometimes feel a bit helpless”. Another participant pleads: “There is no rest- even during rainy and stormy weather and during Christmas times”. All these responses indicate a sense of fatigue and overextension.

However, the access to ARV’s from the Department of Health seems to have given many caregivers hope and is qualified by the following responses: “I’m not actually doing anything for them because they have got CD4 count and have been put on ARV’s and they have improved, so its really very much better” and “It has made our lives lighter because when I started we used to have so many deaths and those deaths affected us” .

4.3.2 Role change as a result of caregiving



The following table looks at how caring for a PLHA has affected the caregivers roles and activities of daily life:

Table 7: Themes and categories of role change of caregiver’s since caregiving (question 7 of focus groups)

THEME	CATEGORY
Things have changed in the community	<ul style="list-style-type: none"> • Help from Bethany house • People are dying
It has affected my roles at home	<ul style="list-style-type: none"> • Family • Carer for children • Home life • Home responsibilities • Parent
I am also sick	<ul style="list-style-type: none"> • I am a HIV positive caregiver

<p>It has evoked something in side of me</p>	<ul style="list-style-type: none"> • You have to be strong for people • You want to help
<p>The changes have been a burden</p>	<ul style="list-style-type: none"> • Why worry about sick people? • We've been struggling for too long • Great burden • My heart is sore • There is no rest • It makes me angry

From this table it is clear that many caregivers have experienced significant role changes as a result of caregiving. Many feel that this is a burden. In one of the focus groups, a participant was sharing her story of becoming HIV positive and how she feared she would not ever see her daughter finishing school. This evoked deep emotions in another participant who started crying uncontrollably. When she could eventually speak, she said it had reminded her of her own daughter who had died of HIV/AIDS. She had never been able to share the cause of death until this point.

Folkman (2003) believes that one needs to research whether someone is functioning in their various roles to determine whether they are coping or not. Thus those not functioning in their roles are presumed to be not coping.

A study by OXFAM (Rajcoomar, 2005) explores how HIV/AIDS has affected the lives of rural grandmother caregivers. Their study shows that, “A complete reversal of roles has occurred, where the elderly now care for the sick and dying members in their family and rear their orphaned and vulnerable grandchildren. For the majority of the elderly a future where they are cared for by their family in their old age is virtually non-existent.” (p.4) CCP caregivers have experienced similar role-change.

4.3.3 Types of stressors

The following graph depicts some of the stressors that caregivers are currently faced with:

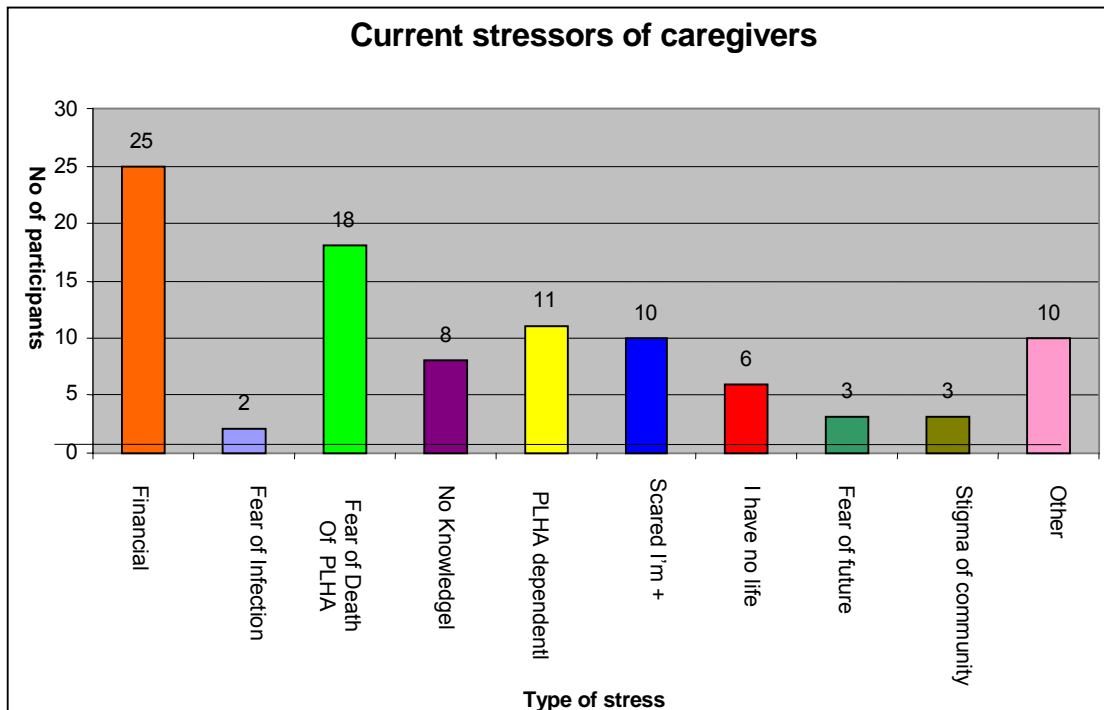


Figure 7: Current stressors of caregivers

As one can see from the bar graph, the main four stressors are financial burdens, fear of death of the PLHA, no knowledge of the right kind of care and having someone totally dependent on them. The “Other” category included the following stressors : the enormity of the problem; struggling to work with other organisations’ mistakes and failures; when people don’t accept their status; not knowing how to solve a problem; growing old; not being heard; (question 16 of questionnaire). The type of stressors caregivers are facing, were qualified in the focus groups. Themes and categories from this discussion are highlighted in the table below:

Table 8: Themes and categories of the stressor’s of caregiving (question 2 of focus groups)

THEME	CATEGORY
People Let You Down	<ul style="list-style-type: none"> • Non-compliance • Clients • Family problems • Children are neglected
Poor Living Circumstances Of	<ul style="list-style-type: none"> • Poverty • Lack Of Resources

Clients And Carers	
Poor care from Department of Health	<ul style="list-style-type: none"> • Clients are turned away from medical help • Health facilities don't provide adequate care
Discrimination	<ul style="list-style-type: none"> • Stigma
Unrealistic Expectations	<ul style="list-style-type: none"> • Dependency of client • Clients' expectations
There Is No Hope	<ul style="list-style-type: none"> • Hopeless communities • People have given up
It's Too Stressful!	<ul style="list-style-type: none"> • Constant stress
Poor Support Networks	<ul style="list-style-type: none"> • No one to talk to

Table 8 indicates that the focus groups uncovered many additional stressors caregivers are faced with that were not documented by the questionnaire.

Joslin, cited in Linsk and Mason (2004), support this data. They describe the unique stressors of caregiver's of PLHA's to be: shame, fear of rejection from the community, caring for the PLHA, fear of death of the PLHA and guilt. Rajcoomar (2005) showed that the main stressors of rural grandmother caregivers are: financial costs of funerals, stigma and discrimination from communities, caring for sick children and adults, lack of or no family support or grief counselling, lack of knowledge of HIV/AIDs and how to protect self from infection, financial burdens of orphaned children. Similar stressors were discovered and unpacked in the focus groups.

There are many costs to caregiving. Kaplin(1996) shows that persons who are caregivers seem to be more prone to a decline in mental health and appear to have an average of two times more psychiatric symptoms than people who do not provide care. Kaplin (1996) highlights the stressors of caregiving to be: conflict within the family, strain on employment , financial burdens, a decreased social life, poor self esteem and a sense of mastery. Again, similar stressors were uncovered in the study. Kaplan (1996) believes that stressors can decrease one's coping resources and states that "The wear and tear nature of chronic stress is likely to wear down resources as part of its effect" (p.57). Thus, these above-mentioned stressors play a major part in affecting a caregivers coping ability.

4.3.4 Effects of caregiving on a caregivers own health

Question 18 of the questionnaire explored what symptoms of burnout caregivers are currently experiencing. This is highlighted in the figure below:

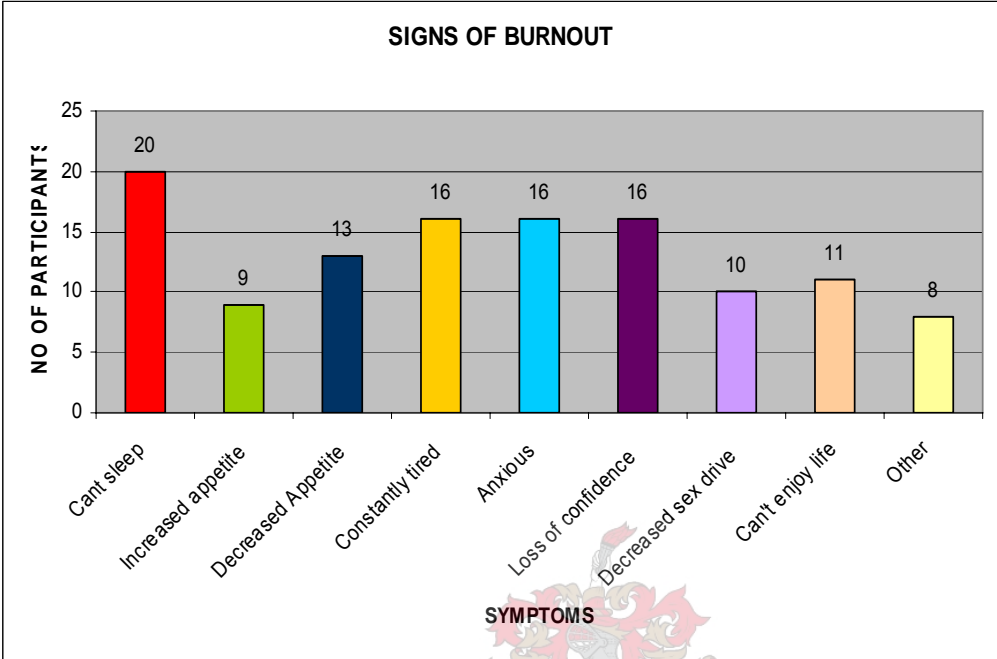


Figure 8: Symptoms of burnout

It is clear from the graph above that many caregivers are experiencing signs of burnout, with 48% of caregivers suffering from lack of sleep. Feeling tired all the time, experiencing loss of confidence in what one does and feeling anxious are also common symptoms that the caregivers are experiencing (38% of all caregivers). 88% of caregivers shared that they are experiencing one or more signs of burnout. This is a warning sign and shows that caregivers do not have sufficient psycho-social support.

Other symptoms of burnout not included in the questionnaire were: not laughing enough; not enough energy to do sport or surf or go to the gym; emotional burnout; seeing people as problems.

Symptoms of depression may include, amongst many others: feelings of sadness; hopelessness; loss of interest in formerly enjoyable activities, including sex; a sense that life is not worth living; significant weight loss and decrease in appetite; weight gain and increase in appetite; insomnia or excessive sleeping; fatigue and loss of energy; a

diminished ability to think, concentrate, or make decisions (<http://www.hivdepression.org>, 2004).

Through the administration of a One way ANOVA test of variance, a significant relationship was found between not being able to enjoy life and whether the caregiver is coping or not. (p-value = 0,010)

Chi-squared test results indicate statistical significance between the number of stressors and number of symptoms of burnout (p-value = 0,005). Thus the more stressors a caregiver is facing, the more likely the caregiver is to show signs of burnout.

A Chi-square test of significance indicated a positive relationship between the following stressors and symptoms of burnout:

Table 9: Positive relationship between variables

STRESSOR	SYMPTOM	SIGNIFICANCE
Fear of HIV infection	Lost confidence in what I do	p=0.022
Fear of HIV infection	Decreased sex drive	p=0.010
Fear of HIV infection	Not being able to enjoy life	p=0.015
Fear of death	Difficulty sleeping	p=0.032
Fear of Death	Tired all the time	p= 0.044
No one to talk to	Decreased appetite	p= 0.032
No one to talk to	Lost confidence in what I do	p= 0.047
No knowledge of right care	Anxious	p= 0.016
PLHA dependent on me	Tired all the time	p=0.017

The following table of themes and categories from the focus groups looks at how caregiving is affecting the health of caregivers:

Table 10: Themes and categories of how caregiving affects a caregivers own health (question 3 of focus groups)

THEME	CATEGORY
Caregiving affects my physical health	<ul style="list-style-type: none"> • Tired • I can't sleep • I feel pain • I get sick
Caregiving affects my Mental Health	<ul style="list-style-type: none"> • I am overwhelmed with emotion • I am mentally not well • I Need Counselling • I am emotionally drained • I have poor concentration • I have decreased motivation • I have lost hope • I have psycho-somatic symptoms
Caregiving affects my Spiritual Health	<ul style="list-style-type: none"> • Spiritual health
Caregiving affects my whole Life	<ul style="list-style-type: none"> • Affects the rest of my life • Affects me when I see my child sick
Caregiving has resulted in me having poor boundaries	<ul style="list-style-type: none"> • I Can't say No • I Can't separate myself from them
Coping Strategies Help protect my Health	<ul style="list-style-type: none"> • Coping Strategies

One can see from Table 10 that caregiving is affecting caregivers' whole lives, including mental health, spiritual health, physical health and ability to have healthy boundaries.

4.3.5 Reasons for caregivers' coping or not coping.

Both the questionnaire and the focus groups asked caregivers if they were currently coping or not and to give reasons for why they were or weren't coping. This is summarised in the following findings:

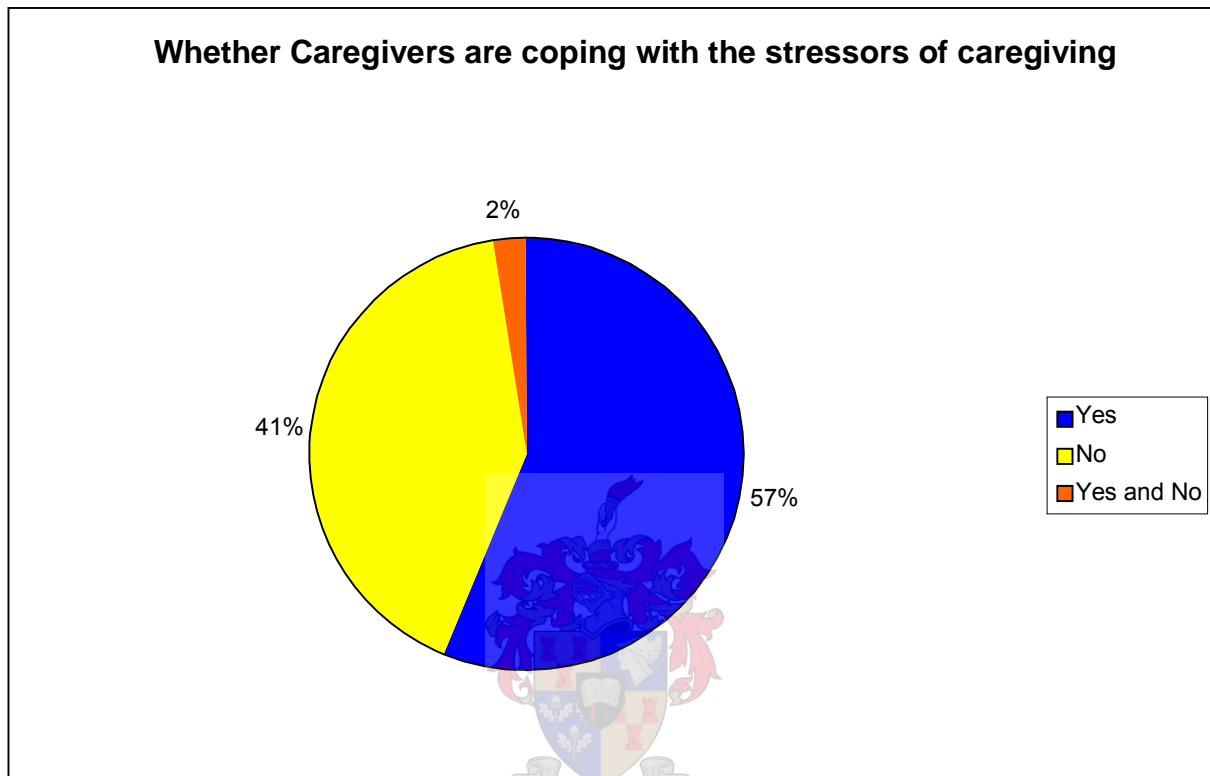


Figure 9: Caregivers perception of whether they are coping or not (question 17, questionnaire)

It is clear from Figure 9 that a very high percentage of caregivers feel that they are not currently coping with the stressors of caregiving (41%). 10 out of 12 tertiary caregivers expressed that they were not coping (83%). Many reasons for coping and for not coping were highlighted from question 4 of the focus groups and question 17 of the questionnaire. The reasons for being able to cope are summarised in the following table:

Table 11: Themes and categories of the reasons caregivers are coping (question 17 of questionnaire; question 4 of focus groups)

THEME	CATEGORY
Spiritually Strong	<ul style="list-style-type: none"> • Spiritual • God helps me • Read Scripture • Pray
Confident in my ability to provide good care	<ul style="list-style-type: none"> • Good knowledge of how to care for a PLHA • Having a positive attitude
Using coping Mechanisms	<ul style="list-style-type: none"> • Time out • Talking with someone I trust • Trying not to bring work home • Everything has its time
Using Support Networks	<ul style="list-style-type: none"> • Debriefing • Good support network
Circumstances aren't too bad	<ul style="list-style-type: none"> • Erratic stress • Little direct contact with PLHA's
Positive Work experiences	<ul style="list-style-type: none"> • When there's a change in a negative situation • I love the work • Positive responses from clients

Some of the reasons why caregivers aren't coping (extracted from question 4 of focus groups and question 17 of the questionnaire) are highlighted in the table below:

Table 12: Themes and categories of the reasons caregivers are not coping (question 17 of questionnaire and question 4 of focus groups)

THEME	CATEGORY
The pressure is too much	<ul style="list-style-type: none"> • The task is too big • I feel overwhelmed • Condition of the PLHA • Pressure of caregiving • No No No this is too much! • Feel I need counselling

	<ul style="list-style-type: none"> • I'm gonna blow
Lack of skills	<ul style="list-style-type: none"> • Not knowing what to do
Personal issues	<ul style="list-style-type: none"> • Unfulfilled desires • Blame self when patient dies • Financial burdens • Attached to the PLHA
Poor access to support networks	<ul style="list-style-type: none"> • Little support
Can't use coping mechanisms	<ul style="list-style-type: none"> • I Can't relax • I Can't switch off
Conditions I have to face in the community	<ul style="list-style-type: none"> • The PLHA is too sick • The circumstances are challenging • The death of the PLHA's • Carers treat children badly
I have Lost Hope	<ul style="list-style-type: none"> • There is no human hope • I am helpless • There is nothing to live for • I don't understand this suffering
I am Frustrated	<ul style="list-style-type: none"> • Families do not accept my help • Your best is not enough • My colleagues are not the same as me and therefore do not understand me

Caregivers seem to have reached the end of themselves. The responses “No no no this is too much” and “I need to stop doing this because it is too much for me”, indicate a huge loss in coping ability and could possibly signify burnout or even depression.

Ravies and Siegal (1991) support the fact that caregivers have a lack of skills and knowledge, which lead to stress, as most caregivers of PLHA'S are not health professionals, but are mainly family members or friends of the PLHA.

Some caregivers did not know if they were coping or not. The reason for their answer is highlighted in the table below:

Table 13: Table showing themes and categories of the reasons caregivers are sometimes coping and sometimes not coping (question 17 of questionnaire and question 4 of focus groups)

<i>THEME</i>	<i>CATEGORY</i>
It depends on what I'm facing	<ul style="list-style-type: none"> • Progress of family • The task is too big sometimes • Depends on the situation

It is hoped that from these results existing support strategies will be deepened, as well as that further intervention, where there are deficits will be introduced, in order to ensure effective psycho-social support and effective coping amongst CCP caregivers. These results will hopefully add to a better understanding of the Management of HIV/AIDS in the world of work as it describes the experiences of employees working with PLHA'S as well as community caregivers.

It is hoped that Government, the private sector, NGO's, CBO's and other HIV/AIDS advocators will be able to address the poor psycho-social support networks that caregivers involved in working against the negative effects of HIV/AIDS.

Chapter four discussed the results of the study in terms of the demographic background of Caregivers, current psycho-social support of caregivers and caregiver's current coping ability. The following chapter makes recommendations for the service at CCP, other organisations working with caregivers of PLHA's and for future research.

CHAPTER 5 : RECOMMENDATIONS

In the focus groups caregivers were asked what would enable them to cope better? This invaluable discussion forms the basis of the recommendation to CCP and is highlighted in the table below:

Table 14: Themes and categories of what caregivers think would help them to cope better (question 6 of focus groups)

THEME	CATEGORY
To be given spiritual support	<ul style="list-style-type: none"> • Spiritual Support • Prayer
Having someone to share my stress with	<ul style="list-style-type: none"> • Counselling • Supervision • Debriefing • Someone to share with
Having space to deal with the stress of caregiving	<ul style="list-style-type: none"> • Time out • Respite
More Support from Bethany House	<ul style="list-style-type: none"> • Support from Bethany House in the Community • Support of me...the caregiver • To be able to go to the community more often • Bethany House to change referral forms • Workplace support
External Input	<ul style="list-style-type: none"> • Being given Motivation • To be given hope

Reidy et al, cited in Rose and Clark-Alexander (1999) explore the needs of caregivers of PLHA's. These include: needing answers to their questions, continuous information about the medical condition of the HIV-positive child under their care, stress management, feeling useful and worthwhile, being supported, having access to respite care and access to psycho-social professional help to deal with their fears and feelings. It is important to take these recommendations from caregivers in order to deal with potential burn-out in its formative stages, when symptoms are less severe. Colleagues are often able to recognise burnout symptoms in an individual before the individual

recognises burnout themselves (Maslach, 1982). Thus the following recommendations are made to CCP:

5.1 FOR THE SERVICE AT CCP

- Continue with supervision, debriefing and counselling with tertiary caregivers, but make this service available to primary and secondary caregivers as well
- Have counselling and debriefing slots available for caregivers to use if needed
- Increased support of primary and secondary caregivers in the community, by CCP employees visiting the caregivers' clients and caregivers more frequently
- Have regular quarterly time-out and respite opportunities for all caregivers, where caregivers are treated and esteemed for their hard work
- Have quarterly stress management and motivational talks to increase the hope of caregivers (this will increase salutogenesis of caregivers- see literature review)
- Evaluate effectiveness of current workplace support and communication channels and adapt if necessary

5.2 FOR OTHER ORGANISATIONS DEALING WITH CAREGIVERS OF PLHA'S AND DEPARTMENT OF HEALTH

It was concerning that only seven participants had access to mental health services in their community, whilst a mere four participants used the mental health department for psycho-social support. It is recommended that the Mental Health Department be more active in advertising its services in the community, as well as targeting caregivers of PLHA's. Without access to this invaluable community resource, caregivers are at extreme risk of burnout and depression. Other organisations working with PLHA's are encouraged to develop an extensive "care of the carer" programme that will incorporate holistic psycho-social support to caregivers of PLHA's, including: supervision, debriefing, individual counselling opportunities, respite, time-out, spiritual support, stress management techniques and external motivation.

5.3 FOR FUTURE RESEARCH

From the results of the research, it can be seen that most caregivers of PLHA are not coping with the responsibility of caring for PLHA's, and are experiencing significant stressors and signs of burnout. Existing programmes at CCP are obviously not sufficient to prevent caregivers from experiencing burnout. Thus the following recommendations are made for future research:

- Research the effectiveness of specific care of the carer programmes in increasing resilience and coping ability (CCP and other organisations that are running similar programmes).
- Conduct a research study at other organisations working with caregivers of PLHA's, to research whether caregivers receive sufficient psychosocial support for maintained coping. Compare the results with this study, to be able to generalise findings to the South African context.
- Develop a model that will train caregivers how to cope more effectively with the stress of caring for a PLHA.
- Many caregivers expressed lack of knowledge of how to care for a PLHA. A model needs to be developed that will look at broadening the knowledge and skills base of caregivers.
- Develop an effective "care-of-the-carer" model that can be rolled out to other organisations working with caregivers of PLHA's.

Chapter five made recommendations to the service at CCP and other organisations working with caregivers of PLHA's and for future research. The following chapter answers the research question and summarises the aims and objectives of the study, whilst making necessary conclusions.

CHAPTER 6 : CONCLUSION

The research question “***Do CCP caregivers, providing care to people living with HIV/AIDS, receive sufficient psycho-social support?***” has been answered by the results of the research. One can see that 41% of CCP caregivers feel that they are not coping at present and 88% are experiencing one or more signs of burnout. Thus the answer to the research question would be, No, many caregivers are not coping and most caregivers are experiencing signs of burnout.

This study aimed to uncover the demographic profile of the caregivers, determine what current psycho-social support is available to caregivers as well as their current coping ability with regards to the stress of caregiving.

According to the objectives laid down, the following points were concluded:

1. The demographic information obtained through the questionnaire will inform CCP of the context from whence their caregivers come.
2. Results show that most CCP caregivers are women of average (mean) age 40.
3. Caregivers are caring for many PLHA's and have dealt with many HIV-related deaths.
4. Most PLHA's are in stage 1 or 2 of HIV/AIDS. It is believed that this is owing to greater access to ARV's, prophylaxis medication and nutrition.
5. The church is the most widely accessible support network (90%) yet only 55 % of caregivers use the church as a support network
6. Caregivers are not using the accessible support networks in their communities, owing to lack of trust and fear of discrimination
7. 71% of caregivers use CCP as their primary emotional support network. This may explain why 83% of tertiary caregivers (staff of CCP) feel they are not coping
8. 41% of caregivers feel they are not currently coping with the stressors of caregiving and 88% are experiencing one or more symptoms of burnout (the most common being insomnia, with 48% of participants experiencing this symptom)
9. The most common stressor is financial burdens. Many caregivers have not received their care-dependency or foster care grants. They need to be assisted in this.

10. Caregivers shared that caregiving has affected their physical, mental and spiritual health.
11. Many caregivers expressed that there had been significant decrease in their role-functioning as a result of caregiving for PLHA's

Some insight into these caregivers' coping ability was gained through this study, however it was realised that there remains a wealth of information yet to be discovered.

In conclusion, in the South African context, where the HIV/AIDS epidemic still sweeps across our nation, devouring many in its path, the role of the caregiver in caring for a PLHA can be an extremely challenging one. Many caregivers are at the risk of burnout as a result of the stress of caring for PLHA's. As found in the study: Mental health services, NGO's, churches and friendship support networks are unable to prevent the burnout of caregivers. This study shows that caregivers of PLHA's are experiencing many symptoms of burnout as a result of caring for PLHA's. One can see the urgent need to develop a model that will help protect the mental health of caregivers and increase the coping strategies of caregivers, to build resilience against the potentially harmful stressors of caring for a PLHA.

This study hopes to promote the rights of caregivers of PLHA's and challenge the Department of Health, NGO's, CBO's, Churches and other psycho-social support services to provide better access to and more comprehensive mental health services, which will ensure that caregivers of PLHA's are provided with the necessary support to ensure maintained coping.

APPENDIX 1

Caregivers' Questionnaire- CONFIDENTIAL

No.

Mark the answer(s) of your choice

1 **How old are you?**

2 **What is your Sex?**

Male	Female
------	--------

3 **Are you a primary caregiver of Person living with HIV/AIDS?** (i.e. providing full-time care)

Yes	No

4 **Are you a secondary caregiver of a Person living with HIV/AIDS?** (i.e. volunteering in your community to provide care such as home-based care)

Yes	No

5 **Are you a tertiary caregiver?** (i.e. work in an organisation that provides support for People living with HIV/AIDS; physical, emotional or spiritual support)

Yes	No

6 **How many HIV positive/sick children do you care for?**

--

7 **How many HIV positive/sick adults do you care for?**

--

8 **Are you the HIV positive/ sick person's:**

Mother	<input style="width: 80%; height: 25px;" type="text"/>
Aunt	<input style="width: 80%; height: 25px;" type="text"/>
Home Based carer	<input style="width: 80%; height: 25px;" type="text"/>
Nurse	<input style="width: 80%; height: 25px;" type="text"/>
Community worker	<input style="width: 80%; height: 25px;" type="text"/>
Counsellor	<input style="width: 80%; height: 25px;" type="text"/>


Colleague	
Friend	
Grandmother	
Other (specify) _____	

9 **The person/people I provide care for are...** (If you provide care for more than one HIV positive/sick person please indicate a number in the column)

HIV positive but healthy	
HIV positive with occasional illness	
HIV positive with frequent illness	
Bedridden	

10 **How many HIV related deaths have you had to cope with?**

11 **In a few brief sentences share what you know about HIV/AIDS and how to protect yourself from HIV infection?**



12 **What is the average monthly income in your household?**

R0-R200	
R200-R500	
R500- R1 000	
R1 000-R2 000	
R2 000-R5 000	
R5 000-R10 000	
Over R10 000	

13 When I feel stressed I...

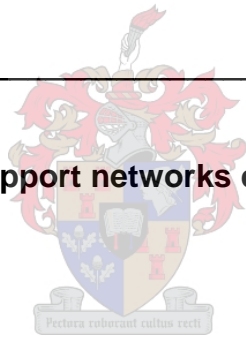
- Talk to someone I trust
- Exercise
- Withdraw to myself and cry
- Do something that relaxes me
- Other(specify)_____
- _____

14 Which of the following emotional support networks do you have in your community?

- Church
- Friendships
- HIV/AIDS awareness groups
- Mental Health Department
- NGO's
- Other_____

15 Which of the following support networks do you currently use?

- Church
- Friendships
- Carers support group
- Mental Health Department
- Bethany House
- NGO's
- Other_____



16 What are your current stressors?

- Financial burdens
- Fear of being infected by the person I care for
- Fear of death of the person I care for
- Not having anyone to talk to when I'm feeling stressed
- Not knowing if I'm providing the right kind of care
- Having someone totally dependent on me

Scared that I may be HIV positive	
Not Having my own life	
Fear of the future	
Fear of what my friends/ neighbours think	
Other _____	

17 Do you feel you are currently coping with the stressors of caregiving?

Yes	No
-----	----

Why or Why not?

18 In the last six months I have the following signs of stress

Not able to sleep	
Increased appetite	
Decreased appetite	
I Feel tired all the time	
Anxious	
I have lost confidence in what I do	
My sexual drive has decreased	
I have lost the ability to enjoy life	
Other _____	



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