# COMPASSION FATIGUE: PASTORAL CARE TO HIV AND AIDS CAREGIVERS WITHIN THE REALM OF THE HEALING PROFESSIONS

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**April 2014** 

#### **Declaration**

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

Signature

Date: April 2014

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# **PROLOGUE**

This study is in recognition and to the honour of all caregivers working in the field of HIV and AIDS, everyone who walks the extra mile and sacrifices so much to care for patients and clients who experience suffering and pain.

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#### Abstract

This dissertation aims to address the phenomenon of compassion fatigue within the scenario – of the HIV and AIDS pandemic in South Africa where an estimated 5-6 million people are living with HIV and AIDS. One in every three patients is hospitalised at some stage of their sickness and sufferers of the pandemic come into contact with someone that gives care to HIV and AIDS infected persons, whether in a hospital, a clinic, in counselling or a hospice. Professional stress and emotional fatigue is an inherent feature of the life of caregivers, and there is growing evidence is that it is on the increase.

Caregivers are generally compassionate people and the compassion that they have and share with suffering people can be depleted. Caregivers become fatigued by the plight and the situation that never lets up hence the concept *compassion fatigue*. In this regard, the meaning of this concept as applied to HIV and AIDS caregivers in the healing and helping professions in hospital care (chaplaincy) and different clinical settings was the focus of the research.

Compassion fatigue relates to professional stress and can impair professional competency and performance within pastoral caregiving. The phenomenon was studied to distinguish between compassion fatigue burnout/burn up and vicarious traumatisation. A more comprehensive understanding of these concepts will help to clarify current misconceptions.

Aspects that necessitate a closer look are whether compassion fatigue is fundamentally stress related or a kind of depletion within the self of the pastoral helper. Could it be some kind of affective exhaustion, or is it related fundamentally to the overexposure to human suffering? Is compassion fatigue then suffering related?

The study focuses on the challenges that confront caregivers in the HIV and AIDS field. How can these challenges pose an existential threat to their being-function and human identity? The study also explores how the theology of the cross (from a pastoral approach) can assist caregivers to deal with the question of *meaning* in the suffering that their patients (and they) may experience.

Research questions included how the phenomenon of compassion fatigue should be understood as an inherent feature of the life of caregivers to HIV and AIDS sufferers, and what caregiving should imply to the caregivers ("wounded healers").

What is clear is that those caregivers very definitely also need care. A viable possibility to render meaningful help to depleted caregivers is to take them out of the working place and give them time, space and means to become whole again. A retreat environment is indicated

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as a form of recuperation for caregivers. At this stage the study amounts to only first steps in that direction and emphasises the need to investigate the subject further.

#### **Opsomming**

Hierdie verhandeling beoog om die fenomeen van medelye-moegheid te verstaan vanuit die agtergrond van die HIV en VIGS pandemie in Suid-Afrika waar daar 'n beraamde 5-6 miljoen mense met HIV en VIGS lewe. Dit word geskat dat 1 uit elke 3 pasiënte in 'n stadium of stadia van die siekte gehospitaliseer word en derhalwe kom die meeste lyers in aanraking met iemand wat sorg verleen aan MIV/VIGS geïnfekteerde persone, hetsy in 'n hospitaal, 'n kliniek, in berading of 'n hospice. Professionele stres en emosionele moegheid is 'n inherente kenmerk van die lewe van versorgers en daar is toenemende bewys dat dit vanweë die erns van die situasie toeneem.

Versorgers is oor die algemeen deernisvolle mense en die deernis wat hulle het en deel met mense wat ly, kan uitgeput raak. Te wyte aan 'n situasie wat toenemend versleg en nie in die afsienbare toekoms sal weggaan nie ervaar versorgers dat die blootstelling aan menslike lyding en ellende hulle vermoë om lydendes pastoraal te troos en by te staan, drasties opgebruik vandaar die begrip *medelye-uitputting*.

In hierdie verband fokus die navorsing op die betekenis van die konsep medelye-uitputting, soos toegepas op MIV- en VIGS- sorggewers binne die kader van die genesing- en hulpverleningprofessies in die hospitaal (kapelaansdienste) en kliniese instellings.

Die verskynsel van *medelye-uitputting* met betrekking tot professionele stres raak die professionele bevoegdheid en prestasie van versorgers in pastorale hulpverlening. In hierdie verband is die doel om te onderskei tussen medelye-*uitputting*, uitbranding en plaasvervangende traumatisering. Dit is aanvaarbaar dat 'n meer omvattende begrip van hierdie konsepte huidige wanopvattings daaroor beter kan toelig.

'n Aspek wat 'n nader beskouing noodsaak, is of medelye-moegheid fundamenteel stresverwant is of 'n soort uitputting van die pastorale helper self, of 'n soort affektiewe uitputting, en of dit verband hou met te veel blootstelling binne die sfeer van menslike lyding.

Die studie fokus op die uitdagings wat deur versorgers in die HIV en VIGSversorgingsveld die hoof gebied moet word, en hoe hierdie uitdaging 'n eksistensiële bedreiging vir hulle kan inhou wat hulle menswees en identiteit negatief kan beïnvloed.

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Die studie verken hoe daar vanuit die verstaan van die kruis-teologie pastorale ondersteuning gebied kan word met die hantering/verstaan van lyding en die doel en betekenis daarvan.

Navorsingsvrae sluit o.a. in hoe ons die fenomeen van medelye-moegheid as 'n ontwikkelende verskynsel in die lewe van versorgers wat met MIV- en VIGS-lyers werk, behoort te verstaan en wat pastorale sorg aan uitgeputte versorgers sou impliseer. Wat duidelik na vore gekom het, is dat die helpende hande baie beslis self ook helpende hande benodig. 'n Haalbare moontlikheid om betekenisvolle hulp aan uitgeputte versorgers te verleen, is aan die hand gedoen, naamlik om hulle uit die werkomgewing weg te neem. By 'n rusplek ("retreat") kan aan hulle die kans gegun word om te herstel, self ook weer heel te word. Hierdie vorm van herstel vir uitgeputte versorgers is kortliks hanteer en word voorgestel, maar dit is maar die eerste treë in so 'n navorsingsrigting, wat die noodsaaklikheid van verdere navorsing beklemtoon.

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# CHAPTER 1 INTRODUCTION

#### 1.1 BACKGROUND

South Africa has an estimated 5-6 million people living with HIV and AIDS. A conservative estimate has it that at some stage of their sickness one in every five of these patients is hospitalised (Van Dyk, 2007:49). The possibility that most or all sufferers of the pandemic will have contact with a caregiver to HIV and AIDS infected persons, whether in a hospital, a clinic, in counselling or a hospice is therefore very real. Caregivers are at the front of the combat lines in South Africa's war against HIV and AIDS. This fact is especially true in rural areas where acute shortages of healthcare professionals exacerbate an already dire situation and the available personnel simply have to make do and cope with the many and varied challenges. More often than not, they are required to operate beyond what is humanly possible. The result is that caring people reach a point where they become so physically, mentally and even spiritually spent that leaving that line of work is very often the only possible decision.

Needless to say, the dwindling of the numbers of these vital links in the caregiving chain only worsens an already very serious situation, as the sheer number of sufferers alone is proof of the burden that caregivers have to bear. For the public the war against HIV and AIDS and the people who have to wage it is mostly only of academic interest and therefore not a matter of concern. More often than not, it would not even be of a casual interest, but the caregivers and other staff that work in the thick of these situations find themselves face to face on a daily basis with the reality of human vulnerability and the stark reality of mortality as part of human existence.

For all personnel that operate in caregiving it appeals not only to the emotional capacity and ministering skills of pastoral caregivers but certainly to the quality of caregivers' being-functions. The plight of the sick and dying forces one into the realm of the *wounded-ness* of the wounded healer caregivers are not robotic workers that can carry on *ad infinitum* and, while they do not suffer the same fate as sickness from HIV and AIDS infected patients, they suffer nevertheless. This phenomenon penetrates the very character of compassion, caregivers

are prone to compassion fatigue: that the very compassion they serve others may actually cause depletion of their reserves of stamina, spiritually, and no less also physically, to maintain their vocation. Although 'compassion fatigue' is not an unheard of phenomenon, relatively little research (within the realm of the healing professions) has been done on subjects that concern compassion fatigue. The researcher has worked through various literature and most reflects on the work done by Figley- therefore the assumption that little or not enough empiral research has been done. The present study may pave the way for further research on assistance to fatigued compassionate caregivers and towards their renewal.

There are laudable socio-political endeavours taking place to combat the pandemic that, as was shown, affects about 10% of our national population. These strategies of the Department of Health (a twenty-year prospect for South Africa where the aim is zero new HIV, AIDS and TB infections; zero deaths associated with HIV, AIDS and TB and zero discrimination related to HIV, AIDS and TB), will tax all the available resources to their limits. The probable outcome in caring for sufferers should foresee immense pressure on caregivers in the Department of Health and health profession overall.

#### 1.2 RATIONALE OF THIS STUDY

Various articles, personal observations (the researcher did an internship at Stellenbosch Hospice for five weeks), and recommendations for future research from other researchers (Koegelenberg, 2004) Zwemstra (2008) indicates in his dissertation that many caregivers are experiencing exhaustion, depression, and even burnout. These observations are a sure indication that caregivers in the field of HIV and AIDS receive insufficient care themselves. It is a matter for great concern, as Van Dyk (2007) found that occupational stress and burnout have a (sometimes devastating,) influence on many caregivers. In South Africa the severity and intensity of the HIV and AIDS pandemic is overwhelming, leaving many caregivers with intense feelings of hopelessness and despair.

The caregivers play an important role in patient care and if the trends mentioned above continues, it may lead to a total collapse of the healthcare and support system. In personal conversations the researcher had with caregivers and from personal observation, one senses their experience of persistent physical and mental exhaustion. Caregivers acknowledge the persistent tiredness that they suffer as burnout and the factors around caregivers' experience present the rationale for this study. Why do caregivers not resign but return to work day after

day, regardless of how rough and tough the previous day's challenges were? Why do they carry on despite the overwhelming exposure to other people's pain and suffering? In the light of this phenomenon, the research explores what compassion fatigue, burnout, and vicarious traumatization mean in the quest to probe the question of how long caregivers might be able to cope.

Aspects of the research include the effect of compassion fatigue, burnout, vicarious traumatization, and compassion satisfaction on pastoral caregivers. An as yet unresolved question is what support they need or can be rendered to help pastoral caregivers deal with their fatigue, caused knowingly or unknowingly by compassion for the sick and suffering, and not just their normal day-to-day tasks.

The pastoral caregivers' own understanding of the meaning of suffering may encourage and inspire them to bring hope to those who have lost hope. There is therefore a particular need for insight regarding the interaction between compassion fatigue and pastoral care-giving that caregivers continue to give despite their own depletion, that the need to care for them who cannot help themselves anymore outweighs one's own interests.

Although not all caregivers are necessarily Christian believers, what they do in these circumstances does accord with the theology of the Cross. On the Cross God's compassion was (and is) demonstrated through unconditional love for those who suffer from the consequences of sin and brokenness. An understanding of God's compassion for the lost and suffering may inspire and motivate caregivers not to abandon being compassionate towards their wards.

#### 1.3 THE RESEARCH PROBLEM

Professional stress and emotional fatigue are inherent features of the life of caregivers. Growing evidence (See chapter 2 with reference to HIV and AIDS deaths) suggests that the frequency may be increasing at an alarming rate. Caregivers are generally compassionate people and the compassion that they have and share with suffering people can become depleted caregivers become fatigued by the plight and the situation that never lets up hence the concept 'compassion fatigue'. In this regard, this study will research the meaning of this concept as applied to HIV and AIDS caregivers within the realm of the healing and helping professions in hospital care (chaplaincy) in various clinical settings.

There is a probability that professional stress within the caregiving professions and the phenomenon of compassion fatigue may be related. Both have a harmful impact and could therefore impair the professional competency and performance within pastoral caregiving. Marchand's 2007 dissertation includes an overview of the history of compassion fatigue, highlighting the various concepts that were current in the past decades. It can be confusing, therefore this is a possibility that necessitates investigation and raises the question whether there is a difference between compassion fatigue, burnout and vicarious traumatisation.

A more comprehensive understanding of these concepts will also clarify current misconceptions about the understanding of the phenomena. An aspect that necessitates a closer look is whether compassion fatigue is fundamentally stress related or a kind of depletion within the self of the pastoral helper. Is it fundamentally associated with the overexposure within the realm of human suffering is compassion fatigue related to other people's suffering? Compassion, as a facet of the sympathy that should be part of the makeup of every normal person and not necessarily a personal religious trait can (contrarily) be regarded as a spiritual aspect.

For the selfless caregiving of the kind that is at stake in the context of this study, taking the plight of sick or less fortunate people to heart to such an extent that the caregivers themselves become needful of compassion, a strongly spiritual nuance comes to the fore. Compassion of this kind reflects what Scripture reveals about God: that He is compassionate and, furthermore, it is an imperative for man to follow (Luke 6:36), it is therefore necessary to afford some consideration to the spiritual aspect of compassion.

# 1.4 RESEARCH QUESTIONS

- a) How should the phenomenon of compassion fatigue as an inherent feature of the life of caregivers to HIV and AIDS sufferers be understood?
- b) What should pastoral caregiving to the caregivers ("wounded healers") imply?

The research question is in itself rather straightforward, but a critical reflection on the scope of the question reveals a complexity of aspects-ensconced in the question. These aspects form the nucleus of this study and as such provide the objectives that the research would accomplish:

- What is the nature of compassion fatigue versus that of burnout, with reference to the healing professions?
- > Is compassion fatigue fundamentally stress-related (over demand) or related to over-

exposure (to care) within the realm of human suffering?

- Is there a connection between compassion and the theology of the Cross? If one has to distinguish between a psychological understanding of compassion (the emotional impact/empathy) and the theological understanding of compassion (as an attribute of God), what is the possible link between an existential understanding of compassion and a theological understanding of compassion? To what extent can a theological understanding of compassion contribute to the process of "healing" and offer a more constructive approach to compassion fatigue?
- ➤ Why do caregivers to HIV and AIDS patients suffer from compassion fatigue?
- Is compassion fatigue a kind of pathology or a normal element of the caregiving task of caregivers in the realm of the healing profession?
- Is compassion fatigue related only to professional occupational stress and trauma (stress-related) or is it related fundamentally to existential crises of human suffering and our quest for meaning and the meaning of life?
- ► How can and should caregivers be cared for?

#### 1.5 RESEARCH DESIGN AND METHODOLOGY

The researcher decided to focus on a literature study due to a lack of sufficient literature in pastoral care that does not address compassion fatigue. Therefore, the researcher aimed to explore this concept within a theological framework for discussion. Louw (2008:135-137) in his book *Cura Vitae* for the first time explains or explores the relationship between compassion fatigue and pastoral care and also human suffering with the theodicy problem as a backdrop. The nature of the study will therefore be of an explorational nature.

The Master's degree do not allow sufficient space, due to time constrains to an intensive empirical study, and therefore the focus is on theory formation. An investigation or evaluation therefore of the concepts surrounding compassion fatigue from a hermeneutical perspective was chosen and Osmer (2008)'s model (or "hermeneutical circle") for practical theological interpretation and exploration serves as paradigm to investigate the questions stated under 1.4.

To put the research in perspective as regards the preferred model, the following detail about

Osmer's model is cursorily pointed out. He puts practical questions about a specific phenomenon and these explorative questions help to discover various dimensions. He sees the pastor as an interpretive guide of situations or episodes. It guides researchers to envisage the ideal situation or at least discover new possibilities for possible further research.

Four basic questions are posed as a guide/framework to answer the research question as stated in 1.4:

- What is going on what is going on in the field of caregiving and overexposure to care that
  leads to compassion fatigue or burnout? This is the descriptive stage and the function of
  priestly listening is the focus here.
- Why is it going on? why do we find that caregivers suffer from burnout or compassion fatigue? The question has an interpretive nature and wisdom is applied.
- What ought to be going on? caring should be a rewarding notion, so what ought to be done to assist caregivers? The question reflects on the normative elements and the function of the pastor is to have a prophetic discernment.
- How might we respond (pragmatic nature) to what is going on? how may we respond from a practical theological perspective to support the notion of caring in the healing profession? The function of this question is Servant leadership.

The exploration of these questions will expedite the interpretation and the response to the situation. The study aims to locate and retrieve a comprehensive collection of relevant research reports and documents that would be sufficient in number for this literary survey. The data from these documents will be analysed and interpreted to gain a better understanding and to seek new insights in an attempt to answer the research question.

## 1.6 THE CONTRIBUTION OF THE STUDY

Although research reports and relevant documentation are available on the phenomenon, the bulk of the material does not fully address compassion fatigue of HIV and AIDS caregivers within the realm of the healing professions from a pastoral care perspective. This research therefore aims to contribute to the field by emphasizing that there is insufficient care and support for workers within the healing profession in their workplace.

A meaningful aspect of this lack of care and support entails the caregivers' understanding of the meaning and purpose of suffering their lives are devoted to the suffering of others while they may or do not comprehend why people suffer, both the direct sufferers and the indirect sufferers, themselves. If caregivers knew why people suffer and understood their own reasons/motivation of their care for those people, it might help to reduce compassion fatigue, burnout, and vicarious traumatisation. While ignorance and incomprehension can cause negative results, or even exacerbate compassion fatigue, knowledge and understanding can help to turn it around and stimulate compassion satisfaction, which in turn may add to caregivers' quality of life.

The concepts that feature in the research title should be conceptualised so that their usage will be clear in the context of the study:

#### Compassion

"A feeling of deep sympathy and sorrow for another who is stricken by suffering or misfortune, accompanied by a strong desire to alleviate the pain or remove its cause" (Figley, 2002:2);

#### **Compassion fatigue**

Exposure to stories of fear, horror, violence, hijacking, and experiences of other people's trauma can backfire on the caring system and create an ontology of trauma (Figley, 1995:11). Caregivers may then suffer from an over-exposure to trauma and develop compassion fatigue ('over-identification');

#### **Compassion satisfaction**

It refers to the challenge and maturity to understand the negative "cost of caring" against a background of the credits or positive "payments" that comes from caring (Figley, 2002:107);

#### **Burnout**

Burnout refers more to exhaustion in terms of professional identity and a feeling of over-whelmed incompetence, caused by accumulative stress (over-exposure) (Figley, 1995:11);

#### Vicarious traumatisation

Vicarious traumatisation is "...when someone starts to experience (in their imagination) the same emotions or actions of another person..." (McCann & Pearlman, 1990:131);

#### Caregiver

The term caregiver in the HIV and AIDS context refers to anyone (professional, lay or family) involved in taking care of the physical, psychological, emotional, and spiritual needs of a

person infected or affected. For the purpose of this study, the term "caregiver" includes everybody who renders a service in the AIDS and HIV context;

#### **Healing professions**

This refers not just to formal places of patient care and treatment but those where people who are infected and affected are assisted by carers in all walks of life in treatment and recovering/healing strategies;

#### Pastoral care

Pastoral care and counselling as the cure of life (*Cura Vitae*) means how we minister to caregivers so that they may experience the basic functions of Christian pastoral care namely healing, guidance, sustenance, reconciliation, nurture and liberation (Louw, 2008:11).

The researcher feels that a hermeneutical understanding of the concepts as discussed in this research may convey a sense of personal healing to caregivers. Furthermore, the research highlights the necessity for a caregiving model that is designed specifically for pastoral caregivers in the HIV and AIDS filed to reduce compassion fatigue, burnout, and vicarious traumatisation in the workplace.

#### 1.7 CHAPTER DIVISION

#### Chapter 1

The purpose of the introductory chapter is to give an outline of the study and it introduces key concepts that are important for this research. The chapter also focus on the purpose and value of this study and how it may benefit giving aid to caregivers.

#### Chapter 2

This chapter's focus is on professional caregiving, healing and revisiting the HIV epidemic. It will promote a better understanding about the paradigm of focus on the HIV and AIDS arena and the impact on caregiving.

#### Chapter 3

In this chapter, the concepts related to the phenomenon of compassion fatigue are explored with a focus on compassion fatigue. It attempts to describe and explore the transforming powers of compassion fatigue: that it is emotionally devastating, how caregivers' personalities

may lead them toward it, the outside sources that cause it that may sometimes be unavoidable and how difficult it may be to recognize compassion fatigue without a heightened awareness of it.

#### Chapter 4

This chapter explores the spiritual dimension of compassion towards a theological assessment of compassion fatigue. The focal point is the compassion of Jesus, which affords a look at the biblical meaning of compassion. The virtue of compassion should lead to compassion satisfaction, but there is the reality of suffering-specifically in the context of the HIV and AIDS pandemic which penetrates the spiritual realm of caregivers and depletes

#### Chapter 5

This chapter examines ways to assist depleted caregivers to move on from depletion (compassion fatigue) to healing (compassion satisfaction). The probable value of a retreat for depleted caregivers' is considered as a ministry model that may assist caregivers to make various life changing shifts in their understanding of meaning and suffering.

Compassion satisfaction is surveyed briefly as the ideal situation and as the 'reward' for caregiving.

Pastoral intervention in the form of pastoral care is investigated, as well as a few methods (practical guidelines not a recipe) of how caregivers may take better care of themselves-

#### **CHAPTER 2**

# PROFESSIONAL CAREGIVING AND HEALING: REVISITING THE HIV AND AIDS PANDEMIC

# 2.1 INTRODUCTION

The HIV and AIDS pandemic within the South African context is not foreign ground anymore, but to put it in context of this study a brief reflection is necessary on what caregivers in the healing profession experience on a daily basis. Despite the widespread effect and consequences thereof, this pandemic has become an almost commonplace item on the South African national scene. Most people know about the pandemic, and many probably know that approximately 20 000 HIV and AIDS deaths occur monthly, but for someone not directly in touch with this horrendous state of affairs the number remains nothing but a statistic.

Families that lose a member or have lost a member/s suffer the sorrow and the reality of the loss. Time and pastoral care will help them heal, but for caregivers that have to deal with all those people dying on a daily basis, the sorrow and the reality are the un changeable facts of their daily existence, making it many times worse.

To gain some insight into the actual state of affairs a brief overview on the pandemic and its decimating effect in the South African context is tendered.

# 2.2 OVERVIEW ON HIV AND AIDS

The AIDS pandemic grew from less than 10 million infected people worldwide in 1990, to about 33.3 million (31.4 to 35.5 million) in 2010. These figures represent an increase of about a third over the period of 18 years (Van Dyk, 2012:7). Although the pandemic appears to have stabilised in most countries of the world, there is no good news for sub-Saharan Africa, since this region remains the most heavily affected in the world (:7). Sub-Saharan Africa accounted for 71% of all new HIV infections in 2009 (UNAIDS, 2009: 8).

The number of people living with HIV in sub-Saharan Africa in 2009 was 22.5 million (20.9 to 24.2 million) with 1.8 million new infections and 1.3 million AIDS-related deaths in that year alone (UNAIDS, 2009:8). According to the same report (UNAIDS, 2009:19) Southern Africa still remains the area most heavily affected by the pandemic and includes the countries with the

highest HIV prevalence in the world: Swaziland (25.9%), Botswana (25%), Lesotho (23.4%), Zimbabwe (18.1%), South Africa (16.9%), Zambia (14.3%) and Malawi (12.7%). South Africa has the largest population of people living with HIV in the world: an estimated 5.7 million. This figure contributes to approximately 17% of the global number of HIV infections.

The adult HIV prevalence for South Africa for 2009 was an estimated 10.6% in the general population. The prevalence rate among pregnant women attending antenatal clinics (ANC) for 2008 was about 29.1% ranging from a high of 38.7% in KwaZulu Natal to 16.1% in the Western Cape. The trends remained stable between 2006 and 2008 with a slight increase in some provinces. The estimate for HIV incidence in the total population was 1.3% in 2008 (Statistics South Africa, July 2010).

The table below indicates the HIV prevalence estimates and the number of people living with HIV, 2001-2010:

YEAR	POPULATION 15-49		Percentage	Total of people
	Percentage of women	Percentage of the population	of the total population	living with HIV in millions
2001	18,7	15,4	9,4,4	4,10
2002	19,2	15,8	9,6	4,38
2003	19,4	16,1	9,8	4,53
2004	19,6	16,3	9,9	4,64
2005	19,7	16,5	10,0	4,74
2006	19,7	16,6	10,1	4,85
2007	19,7	16,7	10,2	4,93
2008	19,7	16,9	10,3	5,02
2009	19,6	17,0	10,3	5,11
2010	19,7	17,3	10,5	5,24

Table 2.1: number of S.A. people living with HIV 2001-2010

The table gives a picture of the situation in South Africa, in that the pandemic began to stabilize for the period 2005-2008, dropped in 2009 and increased slightly in 2010. The accuracy of these statistics remains questionable, however, because they reflect only the numbers of women who attended antenatal clinics. It is very difficult to compile statistics for men because they do not attend clinics or health institutions where records can be maintained. In the Afrikaans News (SABC 2, Saturday, 27/72013) Dr Aaron Motsoaledi, the Minister of Health, was quoted as saying that so far 18 million people have been tested for HIV/AIDS of which only 35 per cent were men. An educated guess could put the figure of sufferers significantly higher. The table indicates that 5.24 million people are living with HIV and AIDS and in the context of this study; that figure is very significant because all of these people may, or will in some stage have to be cared for by people in the health profession. Moreover, the

number may be much higher, and worst of all it is not stable. If it drops there is reason to rejoice, but even a small increase puts a higher burden on caregivers that have to deal with the HIV and AIDS sufferers.

The following table reflects on the number of deaths for the period 2001-2010:

Table 2.2 Number of HIV deaths in S.A. for the period 2001-2010

Year	Number of	Total number of	Total AIDS of	Percentage of
	Births	Deaths	Deaths	AIDS Deaths
2001	1 142 909	526 052	198 030	37,6
2002	1 140 844	569 535	236 390	41,5
2003	1 136 390	609 562	271 488	44,5
2004	1 129 598	645 371	302 530	46,9
2005	1 121 455	661 664	314 196	47,5
2006	1113 087	666 473	314 309	47,2
2007	1 101 612	662 969	306 154	46,2
2008	1 089 916	646 187	284 658	44,1
2009	1 078 767	637 301	270 107	42,1
2010	1 066 401	654 360	281 404	43,0

Reflecting on the above statistics with reference to the total deaths in South Africa the following deductions can be made (and although not supported by hard figures, the very real possibility is that AIDS deaths for men are probably excluded in the overall total). *Firstly*, AIDS deaths made up 43% of the total of deaths in South Africa for 2010. *Secondly*, 11297 more people died of AIDS in 2010 than in 2009.

In terms of health, HIV and AIDS caregivers had to play an important role in taking care of these people as patients. However, the care given would also have had to be extended to their families and communities in terms of counselling, bereavement support, and awareness rendered by HIV and AIDS caregivers in various capacities. Caregivers are therefore responsible for supporting HIV and AIDS patients/clients and families from diagnosis until death and even afterwards.

In South Africa, some 5-6 million people are diseased with the HI-Virus and the very sick with a low CD-4 count of 200 qualify for antiretroviral medication. This CD count was recently adjusted to 350, which means that more people will have access to health care and will visit health care facilities. The table below shows the increase in treatment medication over five years.

Table 2.3: Number of people that need Anti-retroviral treatment

YEAR	Adults (15+ years)	
	Estimated number	
	Receiving ART	
2005	133 000	
2006	239 000	
2007	424 000	
2008	679 000	
2009	920 000	

As cited in Van Dyk (2004:56) the use of anti-retroviral medicines to prevent HIV infection is currently based on approaches: mother to child transmission; post-exposure prophylaxis and ARV's as prevention. ARV medication is distributed by health care facilities and from the above statistics one can deduce that in 2009 920 000 people must have been assisted by caregivers at health care facilities or by home based caregivers in the administering and monitoring of medication (Health Information Epidemiology Evaluation and Research, Department of Health.)

# 2.2.1 Turning point in the South African HIV and AIDS scene

During 2009 President Zuma, with the assistance of the South African government and the Minister of Health Dr Aaron Motsoaledi, committed themselves to implementing the five years National Strategic Plan (NSP) for both HIV and AIDS and Tuberculosis. Several bold commitments to upscale Universal Access were stated, amongst others:

- A revamped South African National AIDS Council;
- Reinforcement of the national goals: antiretroviral access 80% and 50% reduction in new infections by 2011;
- A reinforced tuberculosis plan to address tuberculosis HIV/TB, drug-resistant tuberculosis and strengthening infection control.

New measures were announced on World AIDS Day with 1 April 2010 as the date for implementation. These measures included:

• all children under one year of age to get antiretroviral (ARVs) on a positive HIV test;

- all people with HIV/TB will get ARVs;
- all pregnant HIV positive women with symptoms or with CD4 counts 350 or less will get ARVs;
- all pregnant HIV positive women with no symptoms and with CD4 counts above 350 will be put on ARV prophylaxis from 12 weeks of pregnancy;
- all South Africans will have access to HIV counselling and testing services. Government estimated to test 170 000 people by December 2011.

Unfortunately, some of the goals of the National Strategic Plan (2007) were not achieved and a new National Strategic Plan of Health plan was drafted based on a 5-year period for implementation. The plan looks thus:

#### **Vision and Goals**

The NSP 2012–2016 is motivated by a long-term vision for the country with respect to the HIV and TB epidemics. It has adapted, as a 20-year vision, the Three Zeros advocated by UNAIDS: zero new HIV and TB infections; zero deaths associated with HIV and TB; and zero discrimination associated with HIV and TB.

In line with this 20-year vision, the NSP 2012-2016 has the following broad goals:

- Reduce new HIV infections by at least 50% using combination prevention approaches;
- Initiate at least 80% of eligible patients on antiretroviral treatment (ART), with 70% alive and on treatment five years after initiation;
- Reduce the number of new TB infections as well as deaths from TB by 50%;
- Ensure an enabling and accessible legal framework that protects and promotes human rights in order to support implementation of the NSP;
- Reduce self-reported stigma related to HIV and TB by at least 50%.

(Department of health, 2010/2011.)

With these plans and goals for the South African HIV and AIDS context, it has to be asked critically how these lofty ideals would be implemented successfully. *Firstly*, the health infrastructure is seriously overloaded by patient volumes that very often threaten to become just too numerous to take care of.

Secondly, the health infrastructure is challenged by drastic staff shortages that are further exacerbated by strikes. How will the available personnel cope? Overall, the situation paints a bleak picture that bodes ill not only for people who depend on the health and care giving professions, but those scenarios cannot enhance the lives, the work ethos and the quality of service of the health workers.

Occupational stress is a stark reality for caregivers worldwide. Van Dyk (2007) empirically studied the feelings and perceptions of 243 South African caregivers working in various capacities (nurses, counsellors and teachers) in the HIV and AIDS field. Her findings clearly pointed out the fact that caregivers suffer occupational stress. Over-identification with patients and bereavement overload were two of the main factors.

If these factors are put in perspective of or juxtaposed with the ideals to reduce HIV and AIDS or TB death by 50%, the aim for zero new HIV and AIDS and TB infections and zero deaths associated with HIV/AIDS and TB, the perplexing question remains how it is going to be realised with the existing backlog. Moreover, the present staff will have to cope with the implementation of the challenges, and the consequences to the caregivers' abilities to cope with compassion fatigue, possible burnout and vicarious traumatisation-can only be guesed.

#### 2.3 THE CAREGIVING SYSTEM

Caregivers that lend help to victims of the HIV and AIDS pandemic are considered to be in the frontline of South Africa's response to the pandemic. Their contribution is unseen and might never be recognised. A closer look at the system and the people who have to make it work will put them and their task in clearer perspective. To gain an idea of the challenges they face on a daily basis necessitates consideration of who the caregivers are and how the system of caregiving works.

# 2.3.1 The caregivers

The burden of HIV and AIDS care to help those who have become sufferers is not limited to caregivers in the healthcare professions (Van Dyk, 2012:419; Zwemstra, 2008:30). This burden spills over into communities and forces the informal sector together with professionals in various other capacities to counsel, educate and care for people infected and affected by HIV and AIDS (:419).

The term *caregiver* in the HIV and AIDS context refers to anyone (professional, lay or family) involved in taking care of the physical, psychological, emotional, and spiritual essentials of a person infected or affected (:419). For the purpose of this study, the term "caregiver" includes everybody that renders a service in the AIDS and HIV context.

It does not matter how big or small, any form of aid (formal or informal neighbourhood caregiving) to an HIV and AIDS sufferer that may contribute to his life must be appreciated.

The basic understanding of caregivers in the formal health sector is that caregivers are usually nurses, counsellors, and social workers. It must expand to include lay people and family members and possibly also community members/neighbourhood.

This widening is necessary due to the fact that the number of HIV and AIDS sufferers in South Africa is so vast that very often hospitalisation/formal care is not possible or an option. Consequently, a large portion of caregiving becomes delegated to the community in which sufferers find themselves. It leaves the community no choice but to take care of its own sick. The *informal* (as description of non-medical care) involvement of the groups and people referred to above prompts the question about *pastoral* involvement.

Compassion is not merely a term in the context of the study but is the description of how people are and act towards others. Compassion is the godly attribute that lets people reach out to others and it makes the poignant question that was posed above (p. 5) utterly relevant for communities of faith, ministries and pastoral caregivers who may have to perform a definitive role, especially in rural areas and poor communities. As such, the area for compassion fatigue is broadened drastically and the consideration of the question, *To what extent can a theological understanding of compassion contribute to the process of "healing?"* demands a more constructive approach to compassion fatigue that indeed may impact on all caregivers.

According to DEACSA (2007:44) it is estimated that at the family level the burden of care is predominately borne by women en girls. Although men are also increasingly willing to care for sick partners, however, the least acknowledged caregivers within the family are children.

A holistic view on the what, and who of caregivers reveals that various groups constitute the whole (Van Dyk, 2012:419):

- *Healthcare workers*: mainly doctors and nurses in hospitals, clinics, hospices and home and community based care settings;
- *Nurses, professional and lay counsellors* who assist when and where HIV counselling and testing services are rendered;
- Social workers who work in hospitals or other government organizations;
- *Educators* (e.g. school teachers) who support orphans and other children that were made vulnerable or exposed to AIDS;
- Psychologists and professional counsellors who offer on-going support;
- *Volunteer workers* who work in a formal capacity and offer services such as home and community based care; spiritual care from pastoral caregivers and church members;
- Family members who have to take care of their loved ones at home.

All of the above-mentioned individuals form part of a caregiving network that can be integrated, single service or informal (Uys, 2003:5-7). The care patients can expect is only as strong as the care network. It is understandable that if such networks do not exist in certain areas, caregiving can become a lonely and demanding activity for individual caregivers.

Uys (2003:3-15) explains briefly how these different network models influence caregiving and to understand the notion of caregiving, it is important to elaborate on it. He identified three home and community based care models that give an overview of the terrain and scenarios in which care for HIV and AIDS patients take place:

#### • The integrated or *comprehensive* home and community based care model

This model links all the service providers with patients and their families in a continuum of care. The HIV patient and his family get support from this network of services such as community caregivers, clinics, hospitals, support groups, non-governmental organisations (NGOs), community based organisations (CBOs) and faith based organisations (FBOs) and the larger community. The integrated model therefore allows referrals between all partners as trust is built, and it ensures that community caregivers are trained, supported and supervised.

#### • The single-service home-and community-based care model

This model encompasses one service provider (usually a clinic, hospital, NGO or church) that organises home and community based care by recruiting and training volunteers and connecting them with patients and families at home. Various home-and community based care programmes start this way and later expand to offer integrated care as they recruit other partners. As cited in Magezi (2007:185), Shelp and Sutherland outline the pastoral care of faithbased organisations especially the church. Churches may offer support at a number of different levels, such as: physical or material, emotional or psychological, and what can be most simply identified as spiritual or religious support. According to Uys (in Magezi, 2007:185) AIDS ministries are primarily ministries of support, nurture, and consolation. The caring for human needs is central to pastoral ministry and Uys continues to explain that, using the single service home based care model, churches work out possible ways of reaching HIV and AIDS affected people.

These initiatives by churches/congregations would certainly be crucial in providing support in communities who are poverty stricken and where no external support exists, therefore certain models are better suited to poor communities, where roads are sometimes not well maintained, or where people are isolated or side-lined. There the church can play that role and offer mercy

and compassion to the community in a practical way.

#### • Informal home- and community-based care

In this setting, a family cares for the sick person at home. This happens with the informal assistance of their social network. No formal training or external support is present and there is no formal organisation or supervision of the care. In this setup of informal care, one can understand that care can be very difficult because the primary caregiver often lacks the necessary knowledge, skill and emotional support that are so vital to offer an AIDS sufferer.

Uys (2003:15) feels that the integrated home and community based care model is the ideal model for quality physical care and psychosocial support for patients living with HIV and AIDS and their family.

Uys (2003) illustrates an integrated comprehensive home-and community-based model:

Primary healthcare Health facilities Dispensaries Secondary Community Traditional healers healthcare Orphan care District hospitals NGOs HIV clinics Churches Social/legal Youth groups support Volunteers Hospices PLWHA counselling Palliative, emotional and and testing Specialists and specialised care spiritual support facilities Self-care The entry point Tertiary Home healthcare

Figure 1: Integrated and comprehensive home-and community-based model

Jackson (in Magezi, 2007:185) identifies five models of care that can be considered in conjunction with Uys' model. Jackson sees one of these models as the church based, community outreach model a model that provides an opportunity for the church to offer mercy and compassion to the community in a practical way. If this is not done in love, the people may tend to moralise and increase the stigma. The argument therefore is that when churches or faith

based organisations can show the necessary compassion and identification with people who are suffering (because of poverty and HIV and AIDS), and consider HIV and AIDS sufferers as part of the church, healing is constituted. Faith based organisations and churches play an important role especially in rural areas and poor communities where the necessary health care facilities are non-existent.

The above-mentioned caregiving models illustrate a better and broader perspective of how care takes place and the dynamics surrounding caregiving. On the one hand it shows the significant role that caregivers play to sustain the notion of caring, but on the other it can also illustrate the stress and possible burnout (cf. Miller, in Van Dyk, 2012) among healthcare staff that work with people affected by HIV.

Miller indicates that caregivers and especially HIV and AIDS caregivers are prone to occupational stress. This happens *firstly* due to the nature of their personalities and *secondly* due to the demanding nature of the occupation and exposure to anguish. He further explains that healthcare workers generally have a great sense of commitment to the wellbeing of others and consequently they tend to place a high priority on conscientiousness and work ethic Healthcare workers sometimes find it very difficult to set limits on the demands placed upon them and can lose themselves in their work. The confrontation with the bleak and terrible reality of AIDS often causes them disillusionment.

Van Dyk (2004) conducted an empirical study amongst 250 HIV and AIDS caregivers (nurses, counsellors and teachers) who were enrolled for a course on HIV and AIDS care and counselling at the University of South Africa (UNISA), working in various capacities and localities in South Africa. They had to complete a questionnaire to measure to what extent they experienced the factors inherent in HIV and AIDS work as stressful. The final sample of respondents was pared down to two hundred and forty three, as seven indicated they have no direct contact with patients suffering from HIV and AIDS.

The following factors associated with occupational stress in the HIV and AIDS field were identified and measured:

#### • The overwhelming nature of the disease

Caregivers indicated that the severity and intensity of the AIDS pandemic coupled to the high number of infections, the sharp rise in the mortality rate, the relatively large figure of young people who are suffering and the plight of orphans were of great concern to them. The fact that AIDS is not a disease that affects just the individual but the family and community and the overwhelming nature of the disease often lead to intense feelings of helplessness in caregivers. More than half (51%) felt overwhelmed by the magnitude of the pandemic and this feeling was aggravated by the possibility that they could not help all.

Mazodze, Richards and Pennymon (in Van Dyk, 2012:422) support these findings. They refer to studies done in Zimbabwe for instance, substantiating therapists' despair at the knowledge that their patients were going to die regardless what counselling they provided. According to Smit (2005:25), some South African nurses felt that patients come to the hospital sick, and when they are discharged from hospital they are still sick. It is understandable that caring for persons with HIV can put more stress on healthcare workers than caring for persons with other diseases (Ungvarski & Flaskerud, 1999:282).

#### • Conditions of extreme poverty

HIV and AIDS caregivers especially in Sub-Saharan Africa are likely to feel disheartened by the disempowering effects of poverty (UNAIDS, 2000). Caregivers expressed feelings of helplessness when they have to promote nutritional support in severely impoverished areas, where some patients hardly have enough food for one proper meal a day. Lehmann and Zulu (2005:43) describe that in many instances South African caregivers often give their own lunches or donate money to alleviate hunger amongst the people they care for, or nurses provide clothing from home for babies. In Van Dyk's study (2007:57), nurses told that some families are so poor that paupers' funerals are common. Sometimes burials take place in the backyard where a deceased person lived situations that can be disastrously hazardous for public health.

#### • Over-involvement, over-identification and boundary

Serious problems encountered between caregivers and their clients/patients were over-involvement, over-identification and boundary problems. Almost half of the participants (48.4%) declared that they found it difficult to keep a professional distance and a similar proportion (43.3%) that they often become emotionally involved with the people they cared for.

The study shows that the majority (61.4%) found that to observe the pain and suffering of their clients/patients was very stressful. Some 79.3% of the participants (especially nurses) confessed that they felt the need to rescue or save their clients/patients and could only articulated their frustration in writing at being unable to do so; with others it led to depression

when they considered what would happen to their own loved ones should they become infected.

Caregivers' over-identification with patients can lead to imagining themselves or their loved ones reflected in every patient they treat or counsel. There is a price to pay with over-identification and some become obsessed with the threat posed by HIV and AIDS In turn, this over-identification and obsession lead to mistrust of their sexual partners or their teenagers who are involved in relationships. Their sexual relations became strained when thoughts about their patients/clients intruded when they have sex with their own partners (Van Dyk, 2007:51).

In the same vein, Van Dyk (2007:51) cites Mazodze, Richards, and Pennymon who show that various studies found that counsellors and nurses might even find it impossible to distance them from their patients/clients. They see their own symptoms and problems reflected in their clients, and essentially observe first-hand how they too may become sick and die.

HIV and AIDS caregivers' self-identification with patients was found to be a major factor contributing to occupational stress and burnout (Miller *in* Van Dyk, 2007:51). Some of the caregivers working in the HIV and AIDS field find it difficult or almost impossible to establish professional boundaries between themselves and their clients. This phenomenon is especially prevalent in traditional communities where the extended family system could mean that a caregiver is rarely a stranger but someone who lives amongst the sick and the dying.

The fact that (despite its prevalence on the national public and health-scene), HIV and AIDS is still considered a stigmatised disease, also has damaging influence on caregivers' consciences, and some experience severe stress and guilt due to the emphasis on confidentiality in a work context where they know almost everybody in a particular community (Lehmann & Zulu, 2005:53).

#### • Grief and bereavement overload

Martin (in Van Dyk, 2007:51) found that the most frequently reported ethical dilemma in the field of HIV and AIDS caregiving relates to dying and death. Caregivers live in endless proximity to the death of people with whom they shared some connection. Owing to the demanding nature of their work there is no opportunity to grieve the loss of someone for whom they cared, and often got to know very well.

These factors cause bereavement overload and feelings of guilt for their inability to make a difference in the suffering around them every time a patient dies, that death is perceived by the

caregiver as having failed .There appears to be a strong correlation between the death of clients or patients (especially as regards the number of deaths) and the experience of bereavement overload, grief powerlessness, occupational stress, and burnout in caregivers (Riordan & Saltzer, 1992:17-24).

Although this study concerns people caring for sufferers in the land of the living, the impact of the number of deaths on the profession/s that have to handle the remains of them that passed away can only be imagined. The stress that funeral undertakers have to deal with in their work, the grief of the bereft, often also occupational hazards like striking grave diggers or even a shortage of coffins, are not trivial matters.

#### • Stigmatisation and secrecy

Caregivers working in the HIV and AIDS field sometimes experience isolation, stigma and discrimination, and are often ostracized and avoided by community members, friends and even family because they care for AIDS people (Smit, 2005:26). Owing to ignorance people may think caregivers themselves are contaminated (:26). In Van Dyk's study 32% of caregivers reported that secondary stigmatisation was an issue (Van Dyk, 2007:56), for the caregivers are singled out as "...the AIDS sister..." who should be avoided (:56).

Van Dyk also discloses that 34.6% of caregivers appreciated the necessity for confidentiality although it might be stressful at times. The problems they encountered were that they are not at liberty to talk about their patients. A limiting factor is how to advise someone's family to assist that person when caregivers are not allowed to disclose what is wrong with him. The secrecy surrounding HIV and AIDS and the notion of patient confidentiality causes stress due to the fear of repercussion if one should let something slip.

#### • Professional and role issues

As if caregiving in utterly demanding and taxing circumstances is not difficult enough, organisational factors further cloud the issue (Lehmann & Zulu, 2005:42-47). Various researchers found that occupational stress and burnout in the HIV and AIDS field are sometimes due not only to the severity of everything that pertains to the pandemic, but certain organisational factors take a further toll. The lack of emotional and practical support, lack of supervision and mentoring, role ambiguity due to role expansion, inadequate training, high patient overload, and general workload often cause caregivers frustration, anger, inadequacy and helplessness-(Van Dyk, 2012:47).

In Smit's study (2005) South African nurses who took part in the study expressed concern about the deterioration of public hospital infrastructure (Smit, 2005:25). Negative factors like insufficient medical equipment and medication, hospital understaffing, an ever increasing number of patients in already overcrowded wards, and the fact that they have to perform duties beyond their scope of practice often become too much to bear (Smit, 2005:25).

Van Dyk (2007:57) confirms Smit's findings and indicates that heavy workloads, role expansion, and lack of organisational support contributed to feelings of stress among caregivers. In the study 32.5% indicated that their workload often made it difficult for them to cope (:57). Some reported that they sometimes see 50 patients or more on a normal day doing HIV education, pre-test counselling, or divulging results (of which the majority are positive) (:57). Despite professional precaution, occupational exposure is a constant reality for caregivers and almost half (47.9%) of Van Dyk's participants indicated that they feared accidental infection with HIV (:57).

#### • Frustrations inherent in AIDS caregiving

Uncertainty and rapid change in the HIV and AIDS field cause feelings of occupational stress and burnout with HIV specialists (Gerbert *et al.*, in Van Dyk, 2007:65). Although antiretroviral therapy has brought relief for many HIV and AIDS sufferers, it causes another dimension of occupational stress. Many healthcare professionals in developed countries have described the decisions about drugs, managing drug administration in the face of resistance, witnessing and negotiating side-effects and coping with treatment failure as extremely stressful(:65).

In Sub-Saharan Africa the stress might be related to the fact that caregivers do not have a drug option to offer to their patients, as anti-retroviral therapy is not available everywhere and is often unsustainable. In South Africa, the CD-count to qualify for ARV-therapy was increased to 350, which means that more people will get access to treatment, but in turn this will increase the number of patient visits.

Although great progress has been made in the field of anti-retroviral treatment and prevention programmes, statistics show that the pandemic has merely stabilised. No inroads have been made to curtail infections and the mortality rate due to HIV is still at a grimly high.

When one looks at the mortality figures for 2010 (cf. Table 2.2), 43% of all deaths were due to AIDS (281 404 died of HIV and AIDS in 2010 alone). It could legitimately be postulated that the majority, if not all of the 281404 at some time or another were either counselled, treated,

nursed or supported by some HIV and AIDS caregiver. This total of deaths contributed directly or indirectly to the difficulties the caregivers had to face in their profession.

Lehman and Zulu (2005:53) state that it is not the chronicity of the patients' contact with caregivers that creates an overwhelming feeling but the intensity of the care that is required. One must realise that the prevalence of HIV related illnesses and deaths is a challenge to caregivers to such an extent that questions about their own professional identities cannot be ruled out. The feelings of failure and incompetence would cause anybody to feel out of their depth.

# 2.4 Concluding comments

Although battles were and are being won in combating HIV and AIDS in a variety of aspects, the war is raging on relentlessly. The statistics, reflect the impact the pandemic has on caregiving in the field of HIV & AIDS alone. The Department of Health's integration plan will place more stress on caregivers owing to the fact that limited staff have to reach certain goals. The statistics do not even reflect the other medical and social areas, and other medical conditions such as cancer; diabetes; hypertension; tuberculosis; the impact of violent crime or other primary health care issues of caregiving in the healing professions

The numerous challenges facing caregivers in rural areas or in poor communities with limited resources were also pointed out and one can just imagine how certain caregivers, under difficult circumstances, must offer care to the sick and the dying.

It is in this same war against the overwhelming nature of the disease; conditions of poverty; over-involvement and over-identification; grief and bereavement overload, against survival and coping that caregivers continue to fight and sometimes end up as casualties for a good cause. This background challenges the researcher to wonder: who cares for the caregivers when the statistics or the lack of resources or the intensity of the pandemic and other illnesses are against them?

Caregiving covers a wide range of activity. This perspective broadens the scope of caring for the caregiving community and the forms of compassion fatigue that may be found respectively in each segment of giving care. The various aspects of caregiving are interconnected and they do not operate in isolation, which consequently means that compassion fatigue can have many faces The phenomenon of the depletion of the reserves of caregiving persons, compassion fatigue, is the focus of the next chapter.

#### **CHAPTER 3**

#### THE PHENOMENON OF COMPASSION FATIGUE

#### 3.1 BACKGROUND

-Chapter 2 has discussed the challenges that caregivers must face in their day-to-day work and it is clear that caring for others has both a positive and negative effect on caregivers. As was shown, the scope of caring for people in physical (and no less, also spiritual) need covers a wide and varied field in which one may, on the one hand find fulfillment, but on the other may have to bear much that wears one out. Becoming a nurse, for example, and caring for others can be very rewarding and fulfilling; however, caring for those in need can also lead to severe stress in all areas of nursing (Abendroth, 2011:1). Figley (1995:4) explains that to be continually exposed to stories of fear, horror, violence, hijacking and experiences of other peoples' trauma can backfire on the caring system and can even create an ontology of trauma, where caregivers suffer from such over-exposure and could therefore develop compassion fatigue.

Professional people who have to listen to clients' stories of fear, pain and suffering, may feel similar fear pain and suffering, because they care (Figley, 2002:127) – one person's suffering can affect others secondarily. Caregivers experience rewards for helping others successfully, but when they are strained, or worse, when they fail, helpers/caregivers may become the next casualties to suffer.

# 3.1.1 The effects of working with trauma

There seems to be a variety of negative experiences that people who care for others develop in very negative or traumatic circumstances (cf. Collins & Long [2003:18]; McCann & Pearlman [1990:131]; Figley [1995:2]). Terms such as burnout, occupational stress, secondary trauma or compassion fatigue, vicarious traumatisation or vicarious dramatization, and even traumatic counter-transference (Herman in Collins & Long, 2003:18) are used. Pines (in Collins & Long, 2003:18) named and viewed the problems faced by caregivers simply as burnout.

In this chapter the meaning of the terms/concepts will be scrutinised to develop a broader understanding of the cost and the rewards of caring. Regardless of how they are tagged these terms are sometimes used interchangeably and various literature studies demonstrate that working with trauma victims or people who experience pain and suffering over time, does have an impact on caregivers (Collins & Long, 2003:18).

In the context of and for the purpose of this study, not all the concepts/terms mentioned above will be explored. The terms compassion fatigue, burnout, and vicarious trauma have been singled out.

#### 3.1.1.1 Compassion fatigue

"Compassion fatigue" the concept that is the focus of this study is a relatively new concept (Koegelenberg, 2004:9). It was mentioned for the first time in literature during the seventies. At the time, most publications concerned with the effect of traumatic experiences on counsellors and therapist had paid attention to or focused on the concept of burnout (:9). In 1992, the term *compassion fatigue* was used in an article in the magazine *Nursing* by the health care professional Carla Joinson (1992:116). From a nursing perspective concerning the experiences of people in the caregiving professions on the notion of being physically tired and emotionally drained, she wrote about compassion fatigue as a unique form of burnout.

Other terms in use during this period to explain the impact on the trauma counsellors were Secondary Traumatic Stress (STS) and Secondary Traumatic Stress Dysfunction (STSD). Figley (1995:14) is of the opinion that the term STS best describes the experience or reaction to other people's trauma. He feels that compassion fatigue is a more consumer friendly concept and in a later work (2002) defines compassion fatigue as follows: "[t]he natural behaviours and emotions that arise from knowing about a traumatizing event experienced by a significant other the stress from helping or wanting to help a traumatized person" (Figley, 2002:2).

As such, if stress should develop into compassion fatigue within an existential situation of human suffering it can no longer be viewed as only a professional or occupational phenomenon, because then the suffering of others has touched on the fatigued person's spiritual faculties. Proleptically, one may suggest that compassion fatigue has a 'spiritual' (or theological) dimension that God's feeling towards suffering has sounded an echo in the inner being of caregivers.

To understand the meaning of compassion fatigue it is imperative to explore the meaning of

Posttraumatic Stress Disorder (PTSD) and Secondary Stress Disorder (SSD). Figley (1995:4) describes PTSD as follows:

The essential feature of posttraumatic stress disorder is the development of characteristics and symptoms following exposure to extreme traumatic stress or involving direct personal experience. Events that are involved include threatened death, actual or threatened serious injury, or other threat to one's physical integrity; or witnessing an event that involves death, injury, or a threat to the physical integrity of another person. Learning about unexpected or violent death, serious harm, or threat of death or injury experienced by a family member or other close associates has the same result.

Figley (in Abendroth, 2011:1) explains that the concept of compassion fatigue is identical to STSD and the equivalent of Posttraumatic Stress Disorder (PTSD) with references to the symptoms, except that compassion fatigue applies to caregivers who were touched by the trauma of others. Caregivers may develop a preoccupation with their clients/patients by reexperiencing their trauma. They can therefore develop signs of persistent arousal, for example, difficulty falling or staying asleep, irritability or outbursts of anger and/or exaggeratedly startled responses and anxiety as a result of this secondary trauma. The implication is thus that caregivers may be traumatized without being personally threatened or harmed.

STSD and PTSD are not identical as Figley (2002:19) sets out:

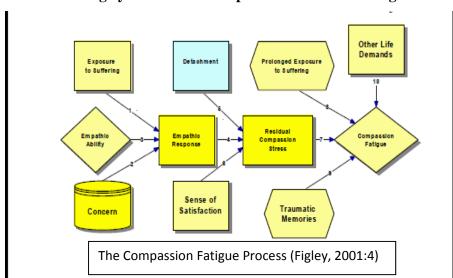
PSTD should be called primary posttraumatic stress disorder, whereas the same symptoms appearing secondarily to victim care in helpers should be called secondary traumatic stress disorder (STSD). The only difference PTSD and STSD was that in latter, exposure was to the traumatized person(s) rather to the traumatic event itself, and intrusion and avoidance symptoms related to the primary victim's experience, not to one's own.

This finding confirms what Figley explained previously: working with traumatised people or being exposed to their stories of pain and suffering affects the caregiver not necessarily because of the event itself but because of the patients'/clients' reaction and the reason/s why they deal with it.

In a pilot study amongst hospice workers Thompson (2007:25) explains that on-going exposure to death and dying appears to create significant risk of compassion fatigue amongst nursing and other staff. Many caregivers experience periods of a significant difficulty that is not attributable to simple burnout resulting from poor working conditions, e.g. heavy case loads, inadequate supervision, or overall mismatch between job requirements or personal values.

It appears that this difficulty is related to the challenges of the continuous engagement with individuals who are grappling with mortality; those who suffer greatly, both physically and psychologically or even those whose family problems have increased by the stresses of coping with terminal diagnoses. Some approaches to compassion fatigue are medically orientated, assuming compassion fatigue to be pathological while others focus on the individual as opposed to the group or the environment.

As cited in Thompson (2006:26) Pearlman's definition of compassion fatigue, which she terms vicarious trauma, avoids both pathologising and individualizing it but acknowledges a spiritual dimension. Trauma and suffering penetrates the spiritual dimension of caregivers and challenges their belief system and their meaning of life. Thompson explains compassion fatigue and vicarious traumatisation as similar concepts and mentions that in vicarious traumatisation due to empathic engagement in other people's trauma, transformation takes place the caregiver's inner experience. She also emphasizes that such responses on the part of the helper are not pathological, but rather a normal reaction to stressful and sometimes traumatizing work.



Figley's Model of Compassion Stress and Fatigue

Figley (2001) presents the model to explain the factors that contribute to compassionate fatigue and how to have a better understanding of the process. Fig.3.1 assists to follow the process that leads to compassion fatigue and will now be explained.

**Exposure to suffering**: due to the exposure to a sufferer's experience an empathic concern is triggered that motivates people to respond to people in need. Caregivers are exposed to the suffering of people on a daily basis due to line of work;

**Empathic ability**: is seen as the aptitude for noticing the pain others experience. This empathic ability elicits an empathic response;

**Empathic response**: refers to the ability or the extent to which the helper makes an effort to diminish the suffering of the sufferer;

**Disengagement**: this refers to the helper's ability to distance him or herself from the continuous misery experienced by the traumatised person;

**Sense of satisfaction**: this refers to the satisfaction or sense of achievement the helper feels due to his or her efforts to help a person in need;

**Residual Compassion stress**: refers to the compulsive demand for action in order to relieve the suffering of others;

**Prolonged exposure**: refers to the on-going sense of responsibility to care for the sufferer, this takes place over an extended period;

**Traumatic memories**: these memories trigger the symptoms of Post-Traumatic Stress Disorder (PTSD) and associated reactions, such as depression and anxiety;

**Life demands**: this refers to the unexpected changes that occurs in schedules, routines and managing life responsibilities that demand our attention (e.g. illness, lifestyle changes, personal, professional or social status);

Compassion fatigue: refers to a state of tension and preoccupation with the traumatised person/patient by (a) re-experiencing the traumatic events; (b) avoidance or numbing of reminders and (c) continuous arousal; and can be seen as a natural consequent behaviours and even emotions resulting from knowing about a traumatic event experienced by someone else. If not managed the caregiver may end up in a compassion trap, which refers to the inability to let go of thoughts, feelings, and emotions long after they were useful.

The above process model shows all the contributing factors and indicates that the caregivers' emphatic ability triggers the process of a reaction. The question arises, whether one should get involved in all the cases of suffering or should-also have the ability to help or assist where one can.

Figley (2002:107-122) also designed a compassion Satisfaction/Fatigue self-test for helpers (see appendix A & B). The purpose of the test is to assist caregivers to get an estimate of their compassion status. The test covers a wide range of questions that really challenge the caregiver to focus on all areas of his or her life and get a picture of the situation. The test can help caregivers to discover how much they might be at risk of burnout and compassion fatigue and the degree of satisfaction they experience from helping others.

#### **3.1.1.2 Burnout**

We often hear how people warn others not to work too hard or to push themselves too hard because they are going to burn out or suffer burnout. Sometimes people experience utter exhaustion and feel frustrated in their everyday tasks and then start to search for other job opportunities where the workload and occupational stress is not so intense.

In the previous section the phenomenon of compassion fatigue was considered as a concept synonymous to burnout. In this section, different points of views on burnout will be considered to discover how it differs from compassion fatigue. According to Maslach and Jackson (1981:397) burnout has traditionally been rooted in an understanding of the interpersonal context of the job itself; specifically the relationship between caregivers and recipients of care and the values and beliefs that relate to caring work as held by care providers.

Maslach and Jackson (in Sabo, 2011:1) define burnout as a syndrome of emotional exhaustion, depersonalization, and reduced accomplishment that can occur among individuals who are involved in "people work" of some kind. Figley (2000:5) describes compassion fatigue as a form of burnout. It would appear that the two concepts differ in terms of nature and intensity. Freudenberger (as cited by Koegelenberg, 2004:13) originally came up with a definition on burnout: "...to fail, wear out, or become exhausted by making excessive demands on energy, strength, or resources." Burnout is more prone in the time we are currently living in due to the amount of continuous adjustments that takes place, the depersonalising of neighbourhoods and work situations (:13).

Sabo (2011:1) theorises on possible factors that may lead to burnout and explains that these factors can be classified according to personality characteristics, work related attitudes, and working/organisational characteristics. Researchers have hypothesized that certain personality traits contribute to burnout, namely: type-A personalities; coping styles, such as escape-avoidance, problem solving, and confrontation; and also traits sometimes referred to as the "big five" namely neuroticism, extroversion, openness to experience, agreeableness, and

#### preciseness.

The individual roles of these factors still have to be clarified. Traits tend to occur in groupings in many individuals but are not always present together. One could consider that certain traits may predispose individuals to increased risk for the development of stress, but further research is necessary to demonstrate whether a causal link does exist.

Another aspect that has been shown to influence the onset of burnout according to Laschinger and Finegan (2005:441) is work-related attitudes. The professional's idealistic expectations, i.e. nursing staff/caregivers' expectations that providing a specific level of care will ultimately lead to positive outcomes for every patient are not only unrealistic and naïve, but may also set nursing staff or caregivers up for stress when they are unable to meet their expected goals. They argue that the incongruence between caregivers' values en beliefs, which often includes their philosophy of care/caring, and the organisation's vision and values may increase the potential of burnout.

Schaufeli and Enzmann (in Van Dyk, 2012:280) also explain that factors like work-related and organisational characteristics may contribute to burnout. Job-related stressors may be in the form of client related stressors (i.e. increased patient perception and complexity); increased patient-to-caregiver ratios; social support factors (the level of education and collaborative practice provided and leader/peer support). Even the degree of autonomy the ability to retain control over decision making in caregiving can contribute to burnout.

From these explanations, one can deduce that while job-related and client related factors are associated with job demands, social support and autonomy are considered potential resources (Schufeli & Enzmannas cited in Van Dyk, 2012:281).

It may be said though that burnout could sprout from a complex set of circumstances as Figley (2002:19) explains:

...it is a result of frustration, powerlessness, and inability to achieve work goals. It is characterized by some psycho-physiological arousal symptoms, including sleep disturbance, headaches, irritability, and aggression, yet also physical and mental exhaustion. Other symptoms may include coldness, pessimism, distrust, problems in work relationships, and falling off, of work performance.

Sabo (2011:1) explains that although a number of theoretical frameworks were proposed to explain burnout, including individual, interpersonal, organisational, and societal frameworks,

research has suggested that no plausible explanation for burnout is to be found in the workplace or organizational environment, but it seems to arise out of a mismatch between the person and the job. Various points of view in the same vein (such as Lehman & Zulu, 2005:53) contend that burnout is due to the competitive nature of work environments and the ever-changing challenges people face, and not necessarily due to the patient/client and caregiver relationship.

Lee and Ashforth (1996:123) mention that early conceptualisations and research on burnout focused on the relationship between the care provider and care recipient as a necessary element in the development of burnout. Herein they would support Sabo. The relationship was regarded as a contributing factor to emotional exhaustion that was thought to be the root cause for burnout. They explain that as research has shifted from descriptive to inferential study designs, findings have strongly suggested that this caring-relationship was not the key driver contributing to burnout.

Research about burnout has consistently supported the existence of a multi-dimensional model that consists of three critical elements, namely emotional exhaustion, depersonalization, and reduced personal accomplishment. These elements are no longer considered to be provider-recipient interactions, because burnout may occur in the absence of such interaction. It could be surmised that burnout may be a precondition for compassion fatigue and vicarious traumatisation, by creating the fertile ground for these types of stress to develop (Sabo, 2006:37).

Logically especially as regards the view that burnout could be the result of a mismatch between the person and the job, the conclusion would have to be that the determinant factor remains the circumstances of anguish of (both patients and caregivers). These might include overwhelming workloads; the inadequacy of both infrastructure and number of personnel to help people are not to blame. Instead, the fault would lie with people who wrongly chose to make nursing and caring for people their life's vocation. They should have contributed to an already negative situation by choosing another life vocation. It appears as if burnout cannot be blamed on difficult working environments and contributing factors, but the people who suffer burnout are their own culprits.

#### 3.1.1.3 Vicarious traumatisation

Vicarious traumatisation can be loosely defined as the situation in which a person starts to experience (in his or her imagination) the same emotions or actions as another person (McCann & Pearlman, 1990:131). Some researchers view it as a convergence of traumatic stress, secondary traumatic stress, and cumulative stress/burnout. Other researchers deal with these as three separate concepts but agree that they are linked to each other in way.

Collins and Long (2003:18) divulge that the concept of vicarious traumatisation was introduced by McCann and Pearlman. They provided a theoretical framework for understanding the complex and distressing effects of trauma work on therapists. Steed and Downing (as cited in Collins & Long, 2003:19) see vicarious traumatisation as the negative changes in the therapist's frame of reference, which are inadequate as a conceptual framework for understanding the full range of effects on caregivers who carry out trauma counselling.

The negativity reported by trauma-workers, whether in a hands-on situation such as nursing, or therapy (such as counselling) seems to figure prominently in discussions of vicarious traumatisation. Pearlman and Saakvitne (1995:151) stated the same in their definition of the (negative) transformation in the therapist's (or other trauma worker's) inner experience resulting from emphatic engagement with clients'/patients' trauma material vicarious traumatisation results in the permanent disruption of the individual's cognitive schema.

Dunkey and Whelan (2006:107) support researchers who suggest that on-going exposure to graphic accounts of human cruelty, trauma, and suffering, as well as the healing work within the therapeutic relationship that is facilitated through "emphatic openness" (as in the case of compassion fatigue), may leave health care providers, including nurses and caregivers, vulnerable to emotional and spiritual consequences.

Thompson (2007:26) treats the consequences of vicarious traumatisation and mentions that it has several features (which could be referred to as 'common' because cases generally display these features). *Firstly*, vicarious traumatisation's effects are cumulative (increasing): the impact of repeated exposure to trauma of whatever sort may gradually change one's beliefs about oneself and the world. *Secondly*, the effects of vicarious traumatisation are permanent. It is of such a nature that it may result in lasting changes in the way people think and feel about themselves, others and the world in which they live . *Thirdly*, the effects can be emotionally interfering and painful helpers/caregivers may find their spiritual belief shifting, including their meaning and purpose in life.

It seems from the various points of view that vicarious traumatisation is more intense and has a more severe effect on caregivers than either burnout or compassion fatigue, and requires more in-depth assistance and counselling when caregivers suffer or reach this level of exposure due to the cost of caring.

# 3.2 RELATIONSHIP BETWEEN COMPASSION FATIGUE AND A CONTINUUM OF OCCUPATIONAL STRESS

There is a level of complexity underlying the various types of occupational stress. This is the conclusion Sabo (2011:4) reached from her observations when reviewing the literature on possible adverse effects of providing care. The complexity may be due to the relatively preliminary understanding of compassion fatigue and the concept about vicarious traumatisation that began to emerge in the early 1990s. There is to date, a lack of empirical evidence to support a theoretical framework for these two types of occupational stress (:4).

Up to the present, there is no research to support a claim that any or all of these types of occupational stress are concept redundant or interrelated (Sabo, 2011:8). It is posited that sufficient evidence/proof exists to demonstrate the validity of each as a distinct concept. What is not clear though, is the role that each of these concepts may play in developing each other. When one reflects on the current theoretical conceptualizations for burnout, compassion fatigue and vicarious traumatisation, Sabo (2011:8) poses the following two questions:

- Is burnout a precondition for compassion fatigue, in other words does compassion fatigue exist on a continuum of occupational stress?
- What happens and to what extent does a non-resolution of compassion fatigue increase the risk for developing vicarious traumatisation?

To try and answer the questions and bring more clarity to the understanding of these concepts in a more practical way, Sabo (in her article "Reflecting on compassion fatigue" [2011]) sketched three scenarios (as presented below) to illustrate how the three concepts (burnout, compassion fatigue and vicarious traumatisation) differ from each other but also how they are in some way interrelated.

#### Scenario 1

A nursing sister worked in an environment where the unit had experienced numerous changes due to fiscal restructuring: two nurse management positions were dismissed, and all nurses on the floor rotated through the dismissed staff members' position for a six months period. The unit no longer had a nurse as manager; instead, several units were combined and with one manager who had no experience in the acute care setting and who did not hold a professional degree in a health related discipline. Nurses' workload doubled, they had to do more overtime shifts, and saw the complexity of patients' increase. The nurses rarely got appreciated, they were stressed, sick time increased, staff turnover was high, and the unit had difficulty attracting new nurses because of increased interpersonal conflicts.

The emphasis in the scenario appears to be an apparent disjuncture between job demand and available resources. The situation describes what Freudenberger (cited in Koegelenberg, 2004:13) identifies about circumstances where burnout occurs: people fail; they wear out or become exhausted by the excessive demands on their energy, strength, or resources. Van Dyk's findings (2007:57) would concur with Freudenberger about the challenges caregivers face as discussed in Chapter 2 concerning professional and roles issues, that a heavy workload, role expansion and lack of organizational support contributed to feelings of stress and difficulty to cope. The most likely outcome of this scenario would be burnout unless the situation could be resolved (Sabo, 2011:9).

#### Scenario 2

Scenario 1 continued without improving; additionally there was added complexity of patient increases and a decline of favourable prognoses; the occurrence of several difficult deaths of younger patients due to too little time to connect with families in crisis caused the level of the staff's emotional distress to increase. Nurses who had been friendly and outgoing were now morbidly reserved and withdrawn. They experienced feelings of guilt over poor patient outcomes; others began to believe that all patients with a specific diagnosis will would die. Management perceived the problem to be related to burnout. Strategies to address the problem proved unsuccessful.

The questions that Sabo poses with reference to the scenario are whether it can be under- stood as a case of burnout, or compassion fatigue. When does occupational stress end in burnout but turns into compassion fatigue? She explains that in this scenario the nurses were experiencing compassion fatigue. She makes the clear distinction again between burnout and emotional

exhaustion (as alternative for compassion fatigue); the latter is held as a cornerstone element along with cynicism and decreased personal accomplishment.

In contrast to burnout, nurses who experience compassion fatigue display an intensified level of emotional distress that may lead to interpersonal withdrawal and changes in their beliefs, expectations, and assumptions. In the scenario, the nurses experienced 'witness guilt' and blamed themselves for their inability to resolve situations, such as easing the pain and suffering of a patient.

In comparing the two scenarios, it is possible that some signs and symptoms may overlap across all three types of occupational stress, although the level of intensity as well as additional symptoms can be helpful in differentiating between them. It could happen that the initial lines blur between burnout and compassion fatigue due to such overlapping but as the situation continues to deteriorate, more signs of compassion fatigue may appear.

Some signs or characteristics of depression are present in compassion fatigue (Sabo, 2011:9). In a recently completed study, she and colleagues observed a statistically significant correlation between the presence of clinical depression and compassion fatigue amongst caregivers of haematological stem-cell transport recipients. Sabo concludes that there is evidence for some overlap between compassion fatigue and depression.

#### Scenario 3

One of the nurses in the above scenarios resigns her job and starts working at a community health clinic 5 believing that a change will restore her physical, psychological, and emotional wellbeing. The clinic is a refuge for abused women and children. Initially the nurse experiences an improvement in her health and overall well-being but the improvement did not last. Every day she encounters grief and sorrow and has to listen to patients' stories of abuse, and it touches her to the extent that images of the patients' experiences intrude in her thoughts.

The once loving and intimate relationship with her spouse suffers badly and touch, particularly, evokes hostile reactions. She experiences fear on occasions she felt panicky when she has to be in the presence of strange men (e.g. while waiting for a bus). Her sense of trust in the compassion and caring of others has changed.

What is happening here? Is this vicarious traumatisation? Can this occur without the presence of burnout or compassion fatigue? The question is whether there is the possibility of vicarious traumatisation without the presence of burnout and compassion fatigue. The signs the nurse experiences (see table below about the signs, symptoms and key triggers of burnout, compassion fatigue and vicarious dramatization) are symptomatic of vicarious traumatisation

(for instance cognitive shift, anxiety, loss of trust, intrusive imagery and changes in values and beliefs). In this situation, it is likely that the nurse is experiencing symptoms associated with vicarious traumatisation.

In their discussion, Dunkley and Thomas (2006:10) agree with Sabo's point of view and mention that vicarious traumatisation can lead to changes in cognitive beliefs schemes, as well as the development of Posttraumatic stress disorder (PTSD) symptoms. They add that other studies have found for example, that a counsellor's case load, range of experience, amount of personal trauma history and coping strategies can influence levels of vicarious traumatisation.

While it is possible that each form of stress may set the stage for the next to occur, behaviour and experience are not linear, nor is the continuum on which burnout, compassion fatigue, and vicarious traumatisation may exist (Sabo, 2011:10). Rather, individuals may move back and forth, at times experiencing symptoms of all three. Currently there is no evidence to support a continuum of occupational stress ranging from burnout to compassion fatigue to vicarious traumatisation. It is also not possible to say that one person, at a given time; can be at only one point on the continuum.

Many, even most caregivers come from a sound personal situation like the nurse in scenario three and could still experience vicarious traumatisation. Sabo concludes her argument and states that it is reasonable to assume that burnout can exist alongside with either compassion fatigue or vicarious traumatisation. What and how each form of occupational stress influences the other requires further research.

Sabo (2011:11) tabulated findings on the signs and symptoms and key triggers in burnout, compassion fatigue, and vicarious traumatisation. It is presented in table 3 below.

Table 3: Signs, symptoms and key triggers in burnout, compassion fatigue and vicarious dramatization

BURNOUT	COMPASSION FATIGUE	VICARIOUS TRAUMATISATION
The gradual wearing down of an individual over time	Acute onset consequence of caring for people who are suffering rather than a response to work environment	Transformation of inner experience and disruption of cognitive schema
Hallmark signs	Hallmark signs	Hallmark signs
Anger and frustration Fatigue Negative reactions towards others Cynicism Negativity Withdrawal	Sadness and grief Nightmares Avoidance Addiction Somatic complaints Increase psychological arousal Changes in beliefs, expectations, assumptions Witness guilt Detachment Decreased intimacy	Anxiety, sadness, confusion, apathy Intrusive imagery Somatic complaints Loss of control, trust and independence Decreased capacity for intimacy Relational disturbances (crossover to personal life)
Physical	Physical	Physical
Psychological Cognitive Relational disturbances	Psychological distress Cognitive shifts Relational disturbances	Psychological distress Cognitive shifts Relational disturbances Permanent alteration in individual's cognitive schema
Key triggers	Key triggers	Key triggers
Personal characteristics Work related attributes Work/organizational characteristics	Personal characteristics Previous exposure to trauma Empathy and emotional energy Prolonged exposure to trauma material of clients Response to stressor Work environment Work-related attitudes	

# 3.3 THE COST OF CARING

The cost of caring for people in traumatic circumstances is high. What can be more traumatic to both a sufferer and the caregiver than the reality of death and dying? In his book *Compassion Fatigue*, Figley (1995:1) shows the cost of caring for professionals who (for example) have to listen to clients' stories of fear, pain and suffering. They are not exempt from the emotions that go with stories of fear, horror, violence, hijacking *et cetera* and which may have a similar impact on them, albeit without their actually having those experiences. This on-going exposure of caregivers to other people's trauma can eventually backfire on the caring system and the development of an ontology of trauma cannot be ruled out. Caregivers may then suffer from an over-exposure to trauma and develop compassion fatigue (:1).

As cited in Van Dyk (2012:426), Hayter and Ferreira explain that the constant exposure to death and dying and not being allowed the opportunity or time to grieve often results in bereavement overload. Caregivers feel that they can no longer make a difference and start to see death as a personal failure. Researchers have found a strong correlation between the death of clients or patients (especially the numbers of individuals dying) and the experience of bereavement overload, grief, powerlessness, occupational stress and burnout in caregivers.

Bennet and Kelaher (cited van Dyk, 2012:326) found that it was especially over-identification with clients/patients which places caregivers in a position of emotional risk of bereavement-overload. In a study done by Van Dyk (2012:326) caregivers admitted that they battle with bereavement, death, and dying issues. Figley (2002:7) explains in detail what the cost of caring is and that caregivers' complete being is affected and sometimes even altered owing to compassion to those in need.

Caring may lead to compassion fatigue, burnout or vicarious traumatisation and may manifest and impact upon caregivers at cognitive, emotional, behavioural and spiritual levels. It also influences personal relations, work performance and personal vital signs.

In her article (2010) "When caring stops, Staffing Doesn't Really Matter" Douglas gives an overview on the cost of caring and what should be taken into an account when caregivers suffer the loss of their ability to continue to care. Douglas tries to warn that caregiving is more than just the operational side of caregiving institutions and that even when organizations develop new technology caregivers are sometimes left behind in their own development.

According to Douglas (2010:415) staffing is core and essential to effective, quality health care

delivery to meet the needs of patients. She argues that although huge investments are made to understand structures, processes, operations and technology of efficient staffing programmes, the importance of the staff member as an individual is sometimes overlooked. If an individual is not qualified, engaged or able to offer the care necessary for healing, the whole health system will unravel, because at the core of an effective care system are the people who staff it.

The behaviour and mind-set of caregivers has an impact on the work that they do (Douglas, 2010:415); therefore the strengthening, the emotional well-being of the caregiver and on-going monitoring, coupled with recognition of issues and appropriate intervention are vital to the management of a caregiver team. She argues that one is able to recognise intuitively when a caregiver is out of balance, emotionally spent, or has lost the capacity for compassion. It is not clear how often this happens to an individual, how well it is recognised, what the influence is on the staffing and assignments and the necessary intervention necessary to bring the individual back into balance. It is therefore crucial that there is a better understanding of an individual or team's emotional exhaustion, apathy, loss of compassion and capacity to care.

Nelson was quoted in Douglas (2010:416) as saying that there is a growing global interest in understanding the caregiver in terms of the role of caring, compassion, and love in care delivery. He argues that there is a need to understand the relationship between when somebody feels cared for and physiological responses that support healing. The understanding of this relationship should be translated into a business case for health care.

Douglas, (2010:416) supports Nelson's views but adds that the role of caring impacts on the patient as well as the caregiver. For example: when the caregiver has to support a fellow human being though fear, pain and loss this may result in his own burnout, or leaving the profession or delivering ineffective caregiving due to the loss of compassion. She argues that there is a lack of understanding of the implications on individual caregivers and their frustration when they are unable to provide the care that they believe is necessary.

Douglas highlights the fact that an emotional presence, capacity for caring, and a reasonable level of compassion that a person has, are intrinsic elements of effective care delivery. Although the role of attitude and emotions in the ability of a person to heal are well documented, the effect of caregivers who have lost their compassion-or who are compassion fatigued remains unclear. Douglas (2010:417) divides the warning signs of compassion fatigue, as explained in Self-Care Academy (2010), into three areas: emotional, work behaviours and physical.

*Emotional* signs of compassion fatigue are apathy, frustration, hopelessness, irritability, poor concentration, boredom, anxiety, depression, and isolation. *Work behaviour* signs are tardiness or absenteeism, error rate, being more critical of team members, record keeping being a challenge, and being cynical towards work. *Physical* signs are insomnia, increased susceptibility to illness, short-term memory issues, fatigue, weight changes and the personal use or chemical dependency increasing.

She argues that it is reasonable to assume that most caregivers have a well-developed sense of compassion and caring; however, she warns, not all individuals in the profession are cut out for the work. This is an issue that should be addressed. It is common that a caring individual may have lost his or her ability for caring, for connecting to the compassion within themselves at a given moment, day, weeks, or even years, resulting in some caregivers' shutting off their feelings as a way to cope with their jobs.

Douglas (2010:416) defines compassion as a virtue in which the emotional capacities of empathy and suffering are regarded as a part of love itself and a cornerstone of greater social interconnectedness and humanism, foundational to the highest principles in philosophy, society, and personhood. She argues further that given the nature of health care, the implications of the loss of compassion present huge potential problems for both the health organization as well as for the individual caregiver.

Douglas (2010:417) argues that health organizations should do more to support caregivers and their emotional needs to limit the impact of emotional imbalances on the patients, organizations and the individual caregiver. Nelson (as quoted in Douglas 2010:418) supports Douglas' views and argues that if caregivers are not granted time to process their own feelings and pay attention to their own needs they will take less and less -care of themselves. This may result in emotional or even spiritual depletion that may manifest in sick calls, decrease in productivity, illness, shutting down, losing the capacity to care, or even leaving the profession.

According to Douglas, K (2010:418)

...compassion fatigue is a physical and emotional exhaustion that causes a decline in a person's ability to feel compassion when taking care of others. It is the cumulative result of internalizing the emotions of patients, co-workers, family, and friends. Compassion fatigue is a result of the caregiver being focused on providing care to others and NOT to themselves.

Douglas explains that compassionate human beings have the tendency to give to the point of exhaustion at the cost of their own well-being or health -She avers that a person's capacity for caring and compassion needs an ability to replenish them after giving. Caregivers are responsible for self-care in order to renew their own internal resources that enable them to be present emotionally in mind, body and spirit and to offer compassion. The renewing of internal resources for individual caregivers will differ from person to person. Each person should explore different ways to nourish themselves , but responsibility to do it rests ultimately with the caregiver himself.

Douglas (2010:419) makes four points regarding caregivers: *Firstly*, health care delivery without caring is not acceptable and patients should not be subjected to it. *Secondly*, health care leaders must invest in structures which support healthy processing of emotional situations and managers should be able recognise the warning signs of compassion fatigue. *Thirdly*, caregivers are responsible for taking care of themselves emotionally to circumvent emotional burnout or compassion fatigue because these are threats to their own health and a potential risk for their patients and organization. *Fourthly*, when staffing and assignment decisions are taken, compassion fatigue and emotional exhaustion should be taken into consideration to ensure that caregivers are able to deliver effective care.

# 3.4 COMPASSION AND EMPATHY

Compassion and empathy are viewed as basic virtues in spirituality. These virtues refer to the disposition or attitude that moves an individual to sustain practices and which enables the person who does it to accomplish moral good (Louw, 2008:281). Compassion is an integrative part of caregiving and it is the notion that motivates people to care but that may also lead to compassion fatigue for some caregivers. Caregivers may become confused and frustrated when the very virtue that drives them to care is now causing them to experience the signs and symptoms of compassion fatigue, such as low morale, powerlessness, decreased self-esteem and feeling of failure. Therefore, with reference to the research question, what one would like to understand is why these two virtues could lead to compassion fatigue.

# 3.4.1 Compassion

Blum (cf. Sabo, 2006:137) explains that compassion amounts to a sympathising with someone who finds himself in certain circumstances. While it is to be recognized that no two persons can feel the same about something, the sympathiser's experience/feeling 'coincides' with the person in the circumstances in the context of this study, the caregiver with the sufferer. Furthermore, compassion promotes equality as experiencing compassion advocate an inherent regard and respect for the other as a fellow human being.

If compassion amounted only to feeling then most if not all humans would be able to be compassionate. True and genuine compassion is rather more than just feeling as it rightly emerges in Merriam-Webster's Dictionary (2011) that compassion is: "...a feeling of deep sympathy and sorrow for another who is stricken by suffering or misfortune, accompanied by a strong desire to alleviate the pain or remove its cause... [t]his is the kind of compassion that motivates caregivers to commit themselves to care for people that are unable to do that for themselves."

Van der Cingel (2009:124-136) explains compassion as the acknowledgement of another person's suffering, accompanied by the expression of a desire to ease or end that suffering. Nursing staff/caregivers' main role is to be present and offer care to those who experience the consequences and distress of health problems. This obligation to humanity makes the concept of compassion extremely relevant to nursing or caregiving practices. When caregivers show compassion or express the notion of compassion it suggests the willingness and ability to be in a relationship with another person. This commitment may be a very difficult and debilitating for caregivers, or it may be a fulfilling and energizing experience.

Pain and compassion, Snitkin (2011:1) argues, require deliberate participation and the identification with "it" the suffering. Compassion is seen as the connecting factor between the brain and the heart. Maclean (in Snitkin, 2011:2) explains that it is a fact that the brain and the greatly expanded human neo-cortex is responsible for the uniqueness of human intelligence human crying and laughter as well, and especially the human tendency to perform unselfish acts. The ability to connect with other human beings, understanding their joys, pain and sorrow is what make us human.

Compassion is described as having two basic parts (Hoisington in Snitkin, 2011:2): *firstly*, hearing the suffering of another (empathy) and *secondly*, acting with wisdom in some way to

reduce that suffering. In our understanding of compassion, it is important to take note that compassion is a human emotional and cognitive experience that does not happen to an individual in isolation. Although the notion of compassion contains or requires emotion, it also has a rational dimension but at its core the notion boils down to unselfish participation in some else's suffering.

Hoisington states that compassion represents a spectrum of phenomena experienced within the compassionate space. It is therefore within this spectrum between empathy and wisdom that the compassion space is found. Nouwen (in Snitkin, 2011:3) sets out compassion as acting with wisdom to reduce suffering, as going where it hurts, to enter the place where pain is experienced, to share in brokenness, fear, confusion and anguish.

Compassion challenges us to cry out with those in misery, to mourn with those who experience loneliness, to weep with those whose tears. It requires further that caregivers (and each of us) be weak with those who are weak, be vulnerable with those who are vulnerable and powerless... compassion means a full immersion in the condition of being human with other humans. As such, it fully corresponds with the Hebrew concept *hesed* (translated *merciful* in Matt. 5:7) and of which William Barclay (1975:103) says it is "... the ability to get right inside the other person's skin until we can see things with his eyes, think things with his mind and feel things with his feelings." It is much more than just an emotional wave of pity but comes from a deliberate identification with the other person sympathy in the literal sense of the word (:103) and, ultimately, a living out towards people in need as God did in the supreme instance of *chesed*, namely the coming of God in Jesus Christ (:105).

Compassion then is more than feelings it requires shared experience and action. Fox (cited in Snitkin, 2011:3) takes it a step further and argues that compassion is a moral virtue which embraces every human being. Therefore, some may be inclined to cherish and develop this virtue while others may reject it as a weakness of human nature; in principle it is available to everybody.

Hoisington (cf. Snitkin, 2011:4) concludes by explaining that with the above arguments in mind compassion involves deliberate participation in another person's suffering, not merely identification of the suffering but identification *with it*. He continues that it is the action part that differentiates compassion from empathy and sympathy, and which requires us to think again about its place and value within nursing or caregiving.

James and Samuels (1999:250) compiled statements that describe how people categorise their level of compassion in various stages. These stages are as follows:

- <u>Stage 1</u>: People have compassion because they believe they will be punished if they do not show compassion.
- <u>Stage 2</u>: People have compassion because they want to respond to a situation.
- <u>Stage 3</u>: People have compassion because their community, e.g. family, faith group, neighbours tell them it is the right thing to do.
- <u>Stage 4</u>: People have compassion because their own internal values tell them it is the right thing to do.
- <u>Stage 5</u>: People have compassion because of a deep loyalty to all humanity that extends, unexpectedly, beyond all that appears to divide humans.
- <u>Stage 6</u>: People may argue that they have no choice but to have compassion which they might feel are called to manifest through creation of justice. There is no division between humans, all are one, and all are sacred.

These stages are valuable in indicating how people may show compassion out of guilt or moral obligation or because society expects compassion on occasion.

# **3.4.2 Empathy**

Is it at all possible to be a caregiver without expressing empathy with your clients or patients at all and trying to put yourself in their position in such a way that they may sense that you really care? Empathy, and as already discussed, compassion that must be rewarding attributes to possess, may cause caregivers compassion fatigue and emotionally depletion. Louw (2008:281) therefore considers empathy as part of compassion and explains empathy as the capacity to enter, understand, and respond to another's frame of reference. It is this capacity that may have a negative impact on caregivers' ability to care for their patients if when they are overwhelmed by the cost of caring.

The most critical element with the therapeutic or helping relationship is empathy (Layton 1994:107; compare also Figley, 1995:15). Sabo posits that although in the increasingly complex, technological world of healthcare technical competence is of great importance; it must combine with interpersonal skills such as empathy, warmth and respect, before a patient will sense that health the professional cares.

Truax (1961) elaborates somewhat on what empathy encompasses and says "...accurate empathy involves more than just the ability of the therapist/caregiver, to sense the client's private world as if it were his own..." These aspects corresponds more or less with the concept

of sympathy – to feel *with* someone as Louw and Nida (1988:295 [II]) put it: "... 'to understand completely how one feels' or 'to feel in one's heart just like someone else feels'..." True empathy does not bear on knowing only Truax (in Sabo, 2006:137) says "...[i]t also involves more than just the ability of the therapist to know what the client means...[a]ccurate empathy involves the sensitivity to current feelings and the verbal facility to communicate this understanding in a language attuned to the clients' feelings." Empathy is an attitude that emphasizes communication (Rodgers, in Tolan, 2003:18) and it is a learned skill if one wants to communicate with warmth and sincerity. People may find healing within the empathic relationship.

Figley (as cited in Sabo, 2006:138) explains that caring, compassion and empathy might demand a price from practitioners, reducing their capacity or their interest in bearing the suffering of others. Therefore, underlying the effectiveness of therapy or caring is the ability to empathise, understand, and help the client. Hilfiger (in Sabo, 2006:138) mentions that empathy becomes a double-edged sword for the nurse/caregiver or clinician: on the one hand, empathy facilitates caring work but on the other, the act of caring leaves the caregiver vulnerable to its very act itself. He emphasises this explanation with the statement (that fits in with the cost of caring, 3.3, and the wounded healer aspect): "...we all feel or have felt the distress and isolation. Ultimately, I believe, there is no solution to the problem. All of us who attempt to heal the wounds of others will ourselves be wounded; it is, after all, inherent in the relationship" (:138).

Even though Figley (2002:15-16) sees compassion fatigue as a by-product of the therapeutic/caring relationship, he also mentions four additional reasons (that dovetail with empathy) for why trauma workers/caregivers may suffer from compassion fatigue:

- Owing to the empathetical engagement with the traumatized person,
- As a result of previous re-enactment of own trauma,
- The activation of the counsellor's (or in context of this study, "caregivers") own unresolved trauma,
- When children experience trauma.

Several theories have been proposed but none of them were able to demonstrate/identify conclusively the mechanism which accounts for the transmission of traumatic stress from one individual to another. Figley (2002:124) hypothesizes though that the level at which the caregiver expresses/demonstrates empathy with a traumatized individual plays a significant

role in this transmission Figley (:137) is clear that high levels of cumulative stress (burnout) in the lives of caregivers affects their resiliency negatively therefore making them more susceptible to compassion fatigue.

Baranowsky (in Figley, 2002:137) explains that the "silencing response" of caregivers, which occurs when the patient/clients' experiences and stories become overwhelming, beyond the caregivers scope of comprehension and desire to know, or simply spiralling past their sense of competence. At this stage, caregivers will begin to notice that their ability to listen has become compromised and this is the point when the silencing response has weakened their effectiveness or worth.

# 3.5 THE DILEMMA OF COMPASSION FATIGUE

In the results of the current research, it transpired that compassion fatigue differs from burnout with reference to degree and nature of exposure. The signs and symptoms are sometimes very similar, and in the next part focuses on the challenges caregivers face when they suffer compassion.

Figley (2002:137) explains that secondary traumatization and burnout (which he considers as the two components of compassion fatigue) affects most caregivers at some point in their professional career. These people must then seek help, but the reversal of roles is sometimes a very difficult position for caregivers one in which they, the caregivers, become the dependents who need care

Caregivers are also subject to fears that someone may judge him as unable to cope, or worse, that he is plain lazy or obstinate; to be laughed at would be unbearable when you have given your all and can lead to difficulty in trusting colleagues. These factors contribute to the silencing response and instead of acting as an incentive to seek help, it can prevent caregivers from reaching out for the help they desperately need.

Figley (2002:137) maintains that compassion fatigue includes burnout symptoms and he acknowledges that there are elements unique to compassion fatigue that should be considered sensitively. He describes the primary categories as follows:

- a) Intrusive thoughts, images and sensations;
- b) Avoidances of people, places, things and experiences that elicit memories of the traumatic experience;

c) Negative arousal in the form of hyper-awareness, insomnia, irritability and anxiety.

Personal strength and resilience differ from person to person and some caregivers can endure the transmission of traumatic stress better. Any caregiver who works continually or permanently with traumatized people has no guarantee that he is never going to feel the suffering of others at some stage in his career things can become too much. Then that caregiver's compassion fatigue is going to rob him of his well-being, comfort, purpose, identity and sense of empowerment (Gentry, Baransowsky & Dunning in Figley, 2002:127). These three scholars developed a programme to assist sufferers of compassion fatigue, using a metaphor, "the road back home", to describe a return to wellness, because they believe that the experience of being home in our bodies, our work, our thought and our spirit seems to decrease as symptoms of compassion fatigue increase (Figley, 2002:127).

When considering the signs and symptoms of compassion fatigue (and some of the other phenomena that are interrelated to each other according to Figley) it becomes clear that compassion fatigue can create a crisis, whether physical, psychological, or spiritual, in a caregiver's life. When we focus on the challenges caregivers face on a daily basis in the execution of their duties (chapter 2) one realizes that they are virtually under threat of their own vulnerability.

Different types of crises play a critical role in their lives and continuously influence them negatively. Louw (2012:142) shows that some crises occur suddenly and leave a person helpless and hopeless their existing coping mechanisms are severely overloaded. He defines a crisis as a situation that occurs when our coping mechanisms are challenged. Louw identifies five types of crises that can cause trauma:

#### **Environmental crises**

Environmental crises happen without the direct involvement of human beings. When a river overflows or when an earthquake destroys and kills thousands of people, it is an environmental catastrophe. According to statistics, South Africa lost 281 404 people to AIDS in 2010. One can compare that to a river or earthquake that destroys communities and leaves families and loved ones exposed to trauma and fate. People are dying and there is no cure, epidemiologists and caregivers can only curb the flow of the river with anti-retroviral prevention programmes and care.

#### **Developmental crises**

People are supposed to live through different stages of life from childhood through adolescence to adulthood, midlife and old age. HIV and AIDS is the cause that some people do not even reach adulthood. Old people are supposed to die but HIV and AIDS is not a respecter of age and even children who are in the prime of their lives die. In order to cope with different health crises can indeed be painful and sickness can destroy a person's so-called "sense of aliveness". The AIDS pandemic is incurable at this stage and that makes people aware of their human predicament. This predicament may either revive their human soul and galvanize people to start to resist death, or the opposite, create fear of the isolation of death.

#### **Existential crises**

These crises refer to the experience of despair and anxiety due to loss and trauma that may occur suddenly. In the presence of despair and anxiety, the person becomes aware of nothingness and life seems to be meaningless. The person's soul becomes a victim of guilt and hopelessness and he starts to question the significance of existence. Compassion fatigue seems to rob professionals of their sense of well-being, comfort, purpose, identity and empowerment (Figley [2002:127] with reference to Gentry, Baranowsky & Dunning). Patients and their caregivers may experience these existential crises owing to the impact of the trauma.

#### Psychological crises

Louw (2012:142) explains that the psychological impact of a crisis on the human psyche may cause feelings of exhaustion and depletion/rundown and that a depleted self is an indication of a perception that one can no longer cope with the demands of life. Neurological, chemical, or hormonal symptoms are sometimes caused by psychological crises. He states further that severe psychiatric conditions may lead to total disorientation and the loss of contact with reality.

Self-destructive responses such as depression are the manifestation of a psychological crisis and depression becomes an indication of severe feelings of helplessness. The person (in this case the caregiver) may veer towards retreating from life because of the perception of total loss of control. When caregivers in the healing professions start to lose patients they may feel that they have lost control over their competency and fatigue of the human soul sets in.

#### **Economic crises**

HIV and AIDS cause many patients to become so sick that they are unable to work, possibly resultanting in the loss of their material security. Unemployment and conditions of poverty create an experience of bleakness: life becomes a daily struggle to survive and as discussed previously, caregivers face this reality on a daily basis when they are confronted with the desperation of the people they need to care for, their living conditions and malnutrition.

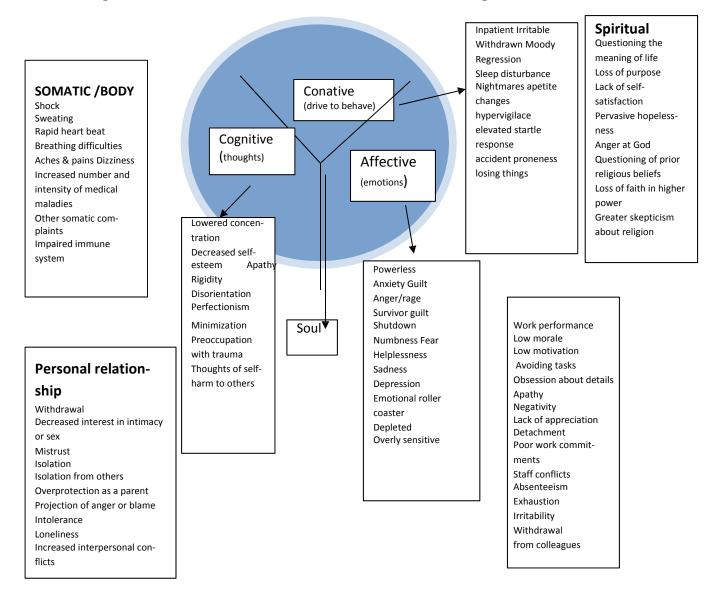
These crises may lead to or create spiritual crises for some caregivers because their only source of hope, strength and even their faith are strained to a breaking point. When caregivers start to question the meaning of life, experience loss of purpose, a lack of self-satisfaction exists; persistent feelings of hopelessness and becoming angry with God crop up. They start to question prior religious beliefs; lose faith in God and become sceptical about religion a spiritual crisis develops (Figley, 2002:7).

The researcher is of the opinion that although caregivers do not experience it personally or directly, the above crises and the evidence of what it does to other people in crisis, also impact on them and invade their own sense of security. In the HIV and AIDS pandemic patients may experience their HIV-positive result or resistance to ARV medication as a crisis; but as has been shown, the caregiver who deals with the situation of testing, making results known and offering health care, may experience the crisis of compassion fatigue-

The suffering of patients, of children and the death of patients may affect caregivers negatively and may even create feelings of guilt, feelings that they have lost their effectiveness and they may even lose hope. Compassion fatigue experience as a crisis may affect one's mode of being. The suffering of patients may cause patients but also caregivers to start searching for meaning within the suffering, leading to questions of meaning and the purpose to life. If we focus on the signs and symptoms of burnout and compassion fatigue as described by Figley (2002:7) it explains the magnitude of the crisis people/caregivers experience in various dimensions of their being.

The following figure gives examples of burnout and compassion fatigue its effects on the caregiver and the quest for meaning:

Figure 3.1 The influence of crises on the various dimensions of a person



In figure 3.1 Figley (2002:7) points out how compassion fatigue influences the spiritual dimension (e.g. questioning the meaning of life; hopelessness; anger against God; questioning prior religious beliefs; loss of faith in higher power) of caregivers. Louw (2008:7) explains that a crisis (in this case, compassion fatigue) can be an opportunity for growth in life skills and faith, depending on the caregiver's framework of meaning, perception of life and understanding of God (God images). Therefore caregivers who are angry with God may express inappropriate **God images**, or experience feelings of being abandoned by God ("God is punishing us" or "God has forsaken us"; or "God does not care what happens to me"). A question that might come to mind is "Is God the cause of this suffering and is He now punishing us?" This and other questions of the same ilk cast God in a very negative mould. In chapter five God images will be discussed further in an exploration of how appropriate God images may assists caregivers in times of crisis.

#### 3.6 Concluding comments

Caring demands a large investment of manpower, and organisations should invest in their caregivers by taking cognisance of the warning signs of compassion fatigue, burnout or vicarious traumatisation (as displayed in figure 3.1).

The researcher is of the opinion that the same virtues (compassion and empathy) that are essential in caregiving but which may lead to compassion fatigue, can also be used to motivate caregivers to persevere, due to the internalisation of these virtues that have become part of their identity.

The argument therefore is that compassion is more than feelings it requires shared experience and action and it challenges us to cry out with those in misery, to mourn with those who experience loneliness, to weep with those who shed tears. It further requires of caregivers (and each of us) to be weak with those who are weak, to be vulnerable with those who are vulnerable and powerless.

Finally, one might say that compassion and empathy are essential in the caregiving professions, but that it has a high cost caregivers sometimes pay a high price in their personal life due to their compassion in caring for others. Caregivers may themselves struggle to understand why they who are supposed to care for others are now on the receiving end of

suffering due to the very high cost of caring. In the spiritual realm it may lead to theological questioning, the age-old theodicy problem of "Why, God?" This aspect is treated in the next chapter.

### **CHAPTER 4**

# THE SPIRITUAL DIMENSION OF COMPASSION: TOWARDS A THEOLOGICAL ASSESSMENT OF COMPASSION FATIGUE

# 4.1 INTRODUCTION

In order for certain caregivers to experience compassion fatigue one can assume that to have compassion would be a prerequisite. In other words, some caregivers experience compassion fatigue owing to the phenomenon of compassion.

In order to have a better understanding of compassion fatigue *per se* in this chapter the notion of compassion and specifically the compassion of Jesus will be reviewed.

# 4.2 JESUS AND COMPASSION

Compassion is a particularly important word in the gospels: most narratives about Jesus depict Him as having compassion and being moved with compassion (Borg, 2000:46). For Jesus, compassion was the central moral quality of a life centred in God (:46) and to which his followers should strive Luke 6:36, "...be compassionate as God is compassionate". The message Jesus speaks indicates a way of life grounded in *imitatio dei* a doing after/imitating of God. This reveals the image of God and the ethos of God. The being of God is best understood through compassion and the same mode indicates how we should live too.

Borg (2000:47) states that Jesus considered compassion not as a mere individual virtue but a socio-political paradigm that expresses His unconventional vision of communal human life. He embodied this vision of life in the movement that originated around him.

# 4.3 THE BIBLICAL MEANING OF COMPASSION

Borg (2000:47) explains that in the Hebrew Bible (Old Testament), sacred also to Jesus and the Jews of the present day, the word *compassion* had a rich semantic association. The noun for *compassion* in Hebrew and Aramaic comes from the plural of a noun that in its singular form means "womb". Therefore, compassion is both a feeling and a way of being that flows from the feeling (:47). True compassion is similar to the intense feeling a mother has for a child of her own womb (:47), and the nearest a man can experience this intensity is in compassion for his own brother who comes from the same womb.

The *feeling* of compassion is experienced in the loins; in the case of women, this would correspond with the womb and in the case of men, the bowel area. The biblical expression to describe deep feeling, "...his bowls were moved with compassion" bears out the connection between real feeling and compassion. Borg (2000:48) shows that *compassion* means "to feel with" and as the origin of the English word suggests, passion originates from the Latin word that means "to feel" and the prefix com- means "with". In other words to "feel with" what are you feeling? You are feeling the emotions of somebody else in an instinctual way, and one experiences this feeling at a level somewhere below the level of the head (:48) in one's 'heart.'

When one witnesses the suffering of another and you are moved by that suffering to intervene, the "feeling with" leads to compassionate action. Compassion and mercy is are not the same, as many Scriptures refer to mercy (Borg, 2000:48). Borg (:48) summarises this explanation by paraphrasing William Blake, who said that mercy wears a human face and compassion, on the other hand, has a human heart.

Borg (2000:49) further argues that the Hebrew Bible often refers to God as compassionate and always with quality of "wombishness" (a word coined by Borg). Jesus' imperative to "...be compassionate as God is compassionate" (Luke 6:36) is rooted in the Jewish tradition and is a central quality of the image of God. To say that God is compassionate is almost the same as saying that God is like a womb. Borg (2000:49) shows that this phrase suggests a number of connotations metaphorically and evocatively. Likening God to a womb implies that God gives birth to us as humans. Similarly, as a woman who loves the children of her womb and feels for them, God loves us and He feels for His children. This perspective of

God's compassionate nature has a tone of giving life, nourishing, caring, even embracing and protecting.

This is what Jesus tried to explain about God .This also intimates the *imitatio dei*,—being compassionate as God is compassionate is to be like a womb as God is like a womb, feeling as God would feel and acting as God would act, in a life-giving and nurturing way.

Hudson (1999:73) would agree with Borg when he explains that compassion lies at the heart of the authentic Christ-following life. When any spiritual experience whether it is one of solitude and silence, prayer and fasting or even celebration fails to result in a deeper concern for our suffering neighbour, it can hardly be called Christian. Hudson further argues that the crucial test of our relationship with God should always involve the quality of our love for those around us (:73).

If this relationship with God isolates us in such a way that we are insensitive to the painful realities of those around us or preoccupies us with our own well-being such a relationship should be considered with suspicion. On the other hand, our relationship with God finds expression in greater compassion and a willingness to express care, to pass the test for sincerity.

Hudson (1999:73) implements the parable of the Good Samaritan as a measurement of Christ's followers' authenticity in the light of the example taken from the words and deeds of Jesus. He explains that the central message of this parable is hard to miss and argues that participation in the kingdom requires that we share with those around us the same kind of compassion that we have received from God. It is imperative to be humble enough to receive care from unlikely neighbours.

Concurring with Borg's argument, Hudson feels that compassionate caring characterizes the very character of Jesus, His interactions with people, and particularly his ministry to those in distress. Jesus touched the lives of many by His ministry of compassion. He touched the leper with compassion, responded to the hungry, opened the eyes of the blind and looked on the crowds who were like sheep without a shepherd. Hudson mentions that scholars sometimes points out that according to the gospels Jesus was always moved with compassion -The Greek verb *splangchnizomai* reveals the incredible depth of this compassionate response in the Divine heart (:74).

Hudson (1999:74) reflects upon Nouwen's explanation that the *splangchna* is the entrails of the body (commonly called the gut). He explains that this is where our most intimate and intense emotions are located. Both passionate love and passionate hate grow from this 'place.' The understanding therefore is that when Jesus was moved to compassion, the source of all life trembled, the ground of all busted open and the abyss of God's immense, boundless, and immeasurable tenderness revealed itself (:74).

In a nutshell then, Jesus walked and talked compassion and this same compassion and becoming more compassionate should be in us a quality which is made possible only through the transforming power of the Holy Spirit working within us. It is impossible to be compassionate by our own efforts alone, or even change our hearts of stone into hearts of flesh. Compassion cannot be obtained by studying for a degree in compassion. Compassion or being compassionate is a divine gift, made visible in lives of people who respond generously to God and their neighbour.

Hudson (1999:77) states that when believers' lives are touched by the Holy Spirit they become more aware of the suffering and pain of others it is as if the Spirit generates the similar current of awareness that was in Jesus. God's Spirit gradually changes hearts into the likeness of the compassionate Christ. A vital dimension of this compassionate awareness, which began by God's Spirit within the Christian tradition, is the recognition of Christ in the last, the least and the lost (:77). Matthew (25:40) underlines this dimension when in his parable of the last judgment Jesus says, "[t]ruly I tell you, just as you did it to one of the least of these who are members of my family, you did it to me."

Hudson (1999:78) uses Mother Theresa's ministry on the streets of Calcutta as an example of a powerful witness to the compassionate consequences of recognizing Christ in the least of his family. She believed that in caring for the poorest of poor or her suffering neighbour, she was alleviating the on-going pain of Christ in our world.

# 4.4 THE COST OF COMPASSION

It is vitally important to understand that caring for others, showing compassion and responding to their pain and suffering may come at a cost and may drain or deplete caregivers. Hudson (1999:87) shares his own experience as a pastoral caregiver: he experienced severe weariness and the prospect of going to work and perform his responsibilities filled him with

dread, he felt drained, dried-up and hopeless. He relates how he had to face a contradicting conviction about the Christ-following life and at some stage even shocked himself when he said, "I don't want to care for people anymore" (:87). This is a stage that the majority of caregivers reach in some stage of their lives and results when someone thinks naïvely that they can continue to give and give out of themselves indefinitely without replenishing their own lives and safeguarding their own well-being. This brought Hudson to realise that over-caring could be unhealthy and might lead to compassion fatigue (:87).

Hudson (1999:88) ignored three vitally important indicators and it led to the deteriorating condition of his soul. These indicators are:

#### Increasing exhaustion

Caregivers sometimes get caught up in a downward spiral of caregiving activity. They might experience tiredness but instead of slowing down, they seek to work through their exhaustion by driving themselves harder. The energy spent on meeting the needs of others must be replaced, otherwise caring holds a threat for the caregiver.

#### The constant demand from those in need

Sometimes, in the responsibility one feels as a follower of Christ to try to meet the needs of helpless people, one is overwhelmed by the extent of their need. Failure to keep up leaves a feeling of guilt. It then may happen that caregivers try to assuage the guilt and shame by pushing themselves harder and render service with a smile while -feeling resentful towards the constant demand made by those in need. Hudson (1999:88) explains how he became a "...happy servant" on the outside and a suffering martyr..." on the inside." The resentment is not an indication of selfishness but a longing of the soul and a silent cry for help from caregivers in general for nourishment and nurturing.

#### Lack of experiencing joy

The third indicator was the lack of lightness and laughter (Hudson, 1999:88). The compassionate life became a grim and heavy-hearted profession. How can you be happy while there are so many people around you who are suffering? (:88).

Hudson's first-hand experience is borne out by Figley (2002:7) who agrees with the above-mentioned signs and symptoms (cf. Chapter 3) and these help to address the core problem of this research in a practical manner. How should compassion fatigue be understood in order to care for worn out caregivers, attending to needs beyond only the physical or psychological?

*Physical* refers primarily to the immediate circumstances (the sheer overwhelming nature of the pandemic, professional issues, *et cetera*) within which care has to be rendered. The *psychological* would entail aspects like grief, stigmatization, and frustration (both aspects have been elaborated on to some extent in the preceding chapters).

Compassion fatigue however also has a *spiritual* dimension, where caregivers are confronted by the realities of life, health and sickness, and ultimately mortality. These realities almost certainly confront them with their own mortality or questions about the meaning of all. One spiritual aspect (with a definite theological quality) that crops up is the theodicy problem/question. The burning theodicy question why does the good God permit bad things to happen to people, even 'good' people has been with man since the beginning of time. There are more questions than answers and the researcher accepts the premise that as a theological issue, the quest for meaning in suffering hinges on an appropriate theological hermeneutics of our understanding of God and the theodicy-problem.

#### 4.5 FINDING MEANING IN SUFFERING

In our country, with the highest number of HIV and AIDS infected people in Africa, suffering is very real and even more so for those who commit their lives to caring for those suffering of the pandemic. From the discussed literature in the previous chapters, it is clear that the grief, pain or loss of other people affect their caregivers compassion fatigue and possibly burnout as secondary crises are often the lot of caregivers. Suffering tends to reveal and explore our understanding of God and it often challenges us to reassess the purposefulness and significance of our life and, in the context of caregivers' own suffering, to find meaning in suffering.

At the grief that is part of life, the first question that almost everyone asks, believers and unbelievers alike, is why God has let it happen. It is therefore legitimate to accept the fact that a sufferer's perception of God is fundamental-to the way in which he works through suffering (Louw, 2012:12). The question of suffering confronts everybody and no less, with the mystery of God's grace and compassion (:12). During a crisis, or during times of grief, loss, or severe illness, people may struggle with the following fundamental questions (:17):

# 4.5.1 The why-question

Within a spiritual framework a caregiver who is overwhelmed by the enormity of patients' suffering may ask "Why?" Reasons are pursued and identities required who is responsible for the suffering? As regards the caregiver personally, the question can turn to "Why me, God? Why, as a caregiver, must I suffer? My task to care is overwhelming!"

The why-question challenges the appropriateness of the caregiver's God-images and at a theological level, it becomes the quest for an understanding of God's identity for an explanation of suffering. The notion of theodicy surfaces through the *why*.

# 4.5.2 The how-question

Suffering people, even those in the position of caring for them that suffer, more often than not experience-isolation of sorts, where God appears to be remote. How can God be involved in this situation when He seems so far away? To try to understand how God is involved in my suffering and sacrificing of me as caregiver, walking the extra mile, how can the circumstances convince anybody that God really cares and understands?

The how-question tries to understand God's identity, in other words, the question poses the problem, how does God relate to my pain or struggle, and how does He reveal (mode, function and style) His caring presence?

# 4.5.3 The where-question

The where-question does not stand apart from the *how*, and this encapsulates our deep longing to locate God in terms of divine intervention. Where is God in my pain, now that I am feeling so powerless, experiencing fear, depressed, and is this His will? This question almost proposes to get God's address, pay Him a visit and ask Him to explain my situation to me. The desire to comprehend the will of God is sometimes a deep longing to gain control over painful situations.

# 4.5.4 The when-question

Caregivers might ask this question when the challenges of caregiving reaches a breaking

point and the pain/suffering becomes too much – "When will this suffering ever stop? When will people start to act more responsible, when will government policies change to make our task easier?"

# 4.5.5 The what-for/purpose question

One of the biggest problems of most suffering people, or in this case of caregivers, is to understand the sense of suffering: what is the purpose of suffering? How can God be glorified at all by something so grim and morbid as great numbers of people ailing away and eventually dying an early death? To meet the *purpose* question head-on, suffering presents a challenge that it is something that must be accepted, internalized and worked through. Louw (2012:19) explains that incorrect God-images may sometimes be the reason/cause why people find it difficult to apply their Christian faith to painful events. Misunderstanding and inappropriate God-images may lead to pathology of faith for example, wrong expectations regarding God's role and function in suffering, or a naïve interpretation of God-will in suffering (Louw, 2012:19).

A sick faith may become a hindrance in the quest for meaning and this can cause an individual to view God in terms of an inflexible and causal explanatory model. God is then perceived or considered as a logical factor; the original factor behind all suffering (:19). This point of view portrays God as the one who is, in one way or another, behind suffering, in other words suffering is the providence and will of God (:19). A pressing question then becomes one of "...can we use God as an easy way out for all painful questions?" (:20). After all, in Matthew 27:46, does not God Himself become a question in the lament: "My God, My God, why have thou forsaken me?" (:20).

Louw indicates that the theological argument will be that a theology of the cross (theologia crucis) directs us to the identification of God with our human suffering (2011:20). The theology of the cross emphasizes the vulnerability and compassion of a suffering God, and simultaneously on the other hand, how the theology of the resurrection points to the transformation and overcoming of human suffering. Inbody (in Louw, 2012:20) explains that God's power is God's identification with a suffering world and this includes God's own vulnerability, God's powerlessness, and God's compassion.

# 4.6 THE THEOLOGY OF THE CROSS

In the theology of pastoral care, the debate about the theology of the cross is an important component because it engages with the act of God's involvement, solidarity, and identification with suffering (Louw, 2000:73). Louw posits that the theology of the cross essentially launches a vigorous protest against a metaphysical doctrine of a theistic God, a God that who places Himself so high and so far, that those who are suffering feel abandoned by Him.

Hughes (1985:48) explains how in the spring of 1518, in Heidelberg Martin Luther placed his theological paradoxes in explicit opposition to the prevailing theology of the church of his day. The reformer used the formula *Theologia crucis* (theology of the cross) because it focused on the distinctiveness of the gospel over against the prevalent theology, which he called the theology of glory. Luther's understanding of the theology of the cross means that we can or should trust in God's suffering love; while glory suggested clear-cut answers like "works" and merit" (:48). Luther therefore plays an important role in the debate regarding the theology of the cross.

In his *Pastoral care under the cross* Eyer (cf. Louw, 2000:74) posits that the appropriate question in suffering should not be "Why is God doing this" but rather "Where is God in this" where is God in my suffering? When the *why*-question of suffering is contemplated, a question that almost demands God to explain Himself, that question becomes very difficult. In time it has become clear that the pat and easy answers, almost religious clichés, to the why-question that "...God is testing us ...punishing us...teaching us...warning us" rarely, if ever, benefited anyone who experienced hopelessness, helplessness and suffering. Since God's mind is unknown to us, we are in no position to know when or whether these answers were even applicable in given circumstances.

In pastoral care, one should not only ask why people experience pain and suffering but should probe deeper and rather also ask where and how. Is it possible that God is involved in suffering? The answer is, although strange, is yes, God is involved, by way of the cross (Louw, 2000:74).

The theologia crucis bridges the distance between the sufferer and God (Louw, 2000:74). The

purpose or goal of pastoral care under the cross can therefore never be to eliminate suffering, but indeed to point those (caregivers) to God in the midst of their suffering. The theology of the cross reveals God's mode in which He deals with suffering: weakness (:74).

A reflection on the meaning of the cross for pastoral theology and pastoral care for caregivers could be handled then from two different perspectives, namely an existential perspective and a *theo*logical perspective (Louw, 2000:74). In the theological debate with reference to the pastoral importance of the theology of the cross, Martin Luther's *theologia crucis* is a more existential model. He questions the manner in which we know and understand ourselves and God in terms of the suffering of Christ. On the other hand, Moltmann's *eschatologia crucis* is more of a *theo*-logical model, asking the question, who is the Triune God in terms of the suffering of Christ? (Louw, 2000:74.)

# **4.6.1** The existential dimension of the cross: Luther's *theologia crucis*

Luther declared that while a theology of glory speaks well of bad and calls the bad good, the theology of the cross on the other hand describes essential reality and perceives being in terms of its essential characteristics (matter as it is) (Louw, 2000:75). The visible, as well as the not-yet-revealed or future aspects concerning the presence of God should be seen from the perspective of suffering and the cross.

In other words, the cross becomes a resource of knowledge and understanding and in this sense Luther not only defends himself against any natural or self-glorifying theology, but proclaims the pastoral dimension of the cross which therefore means that God relates to human suffering.

Von Loewenich (as discussed in Louw, 2012:75) explains Luther's argument on the theology of the cross as an indication that is not merely a subject of theological discussion, but in itself represents a exactly what theology is all about. He further explains that the cross does not just play a role in our assurance of salvation but that it is the core of all theological statements. Therefore, the cross of Christ and the cross of the Christian belong together. The significance of the cross of Christ is that it reveals the nature (the *how*) of the relationship between God and human beings.

When we look at the cross, our mind tells us that God is hidden (dead) and that there is no God on the cross. Owing to this situation human beings are forced into an absolute state of hopelessness and helplessness (anxiety). This existential disbelief becomes the basis of our faith. In our faith, humans reach out to this hidden God who is present in the humility and shame of the cross. Our faith therefore becomes existential and due to our hopelessness and helplessness it drives us to God. He further explains that Christ's own cry against God and our cry of despair are absorbed in Christ's outcry, and in this we find grace. Between our human suffering and Christ's suffering there is a unique connection which Luther calls "marvellous exchange".

We can remember that Christ faced the cross, and as we contemplate the grim spectacle of His suffering on the cross we realize that he did not undergo the suffering for His own benefit, but for those for whose behalf He had to die.

McGrath (1985:149) explains that although God is not revealed on the cross at all, Luther is correct in saying that God is only recognizable by means of faith and not by means of natural knowledge. Luther therefore puts the emphasis on the mode of God (the *how*) God-with-us and God-for-us, and not the speculation of how may in-and-for-Himself.

The theology of the cross from Luther's point of view shows us that God suffers with us and that God is known especially through suffering; nor is this an -impassive God, but a God of passion and compassion. It also reveals our existential dilemma: that we cannot save (help) ourselves.

# 4.6.2 The ontological dimension of the cross

Moltmann's *eschatologia crucis* is at stake here. Miller and Grenz (1998:115) explain that Moltmann questions the ontic dimension of the theology of the cross, i.e. whether God is only recognizable in the suffering of Christ (identification) or whether He suffered Himself. When one raises this ontological question one starts to wonder whether it is possible for God to suffer; is suffering an ontic category that describes a portion of the pathos and sympathy occurring within God Himself? Is the notion of suffering an essential characteristic of God?

Miller and Grenz (1998:118) elaborate that Moltmann's eschatological *crucis* consists of the theology of the cross, theology of hope and the theology of the resurrection. He therefore

emphasises the resurrection and the eschatology as the sources of acknowledgement for the Christology, because the resurrection becomes the key to, and the exegesis of, the cross. He argues that a theology of hope is essentially a theology of the cross. We need to understand the cross in the light of the resurrection because it reveals the understanding of salvation. It reveals the meaning dimension of salvation, according to him. There can be no theology of hope unless we first acknowledge the theology of the cross.

Moltmann (see Louw, 2000:84) states that suffering can only be overcome by suffering and therefore only a suffering God can help. On the cross, suffering becomes God's active participation in human suffering. A theology of the cross becomes a theology of hope, because Christ Himself suffered victoriously on the cross. Moltmann interprets his Trinitarian theology on the cry of Christ: "My God, my God, why hast thou forsaken me?" Here the forsakenness becomes the primary issue for a hermeneutics of the cross in the effort to reframe God's metaphors in terms of suffering.

God can be best understood only if we understand Him as a suffering God, and forsakenness is essential to His very being. Moltmann posits that in the cry of Jesus, as mentioned, it is not only Jesus who is under threat, but also God the Father. The implication is clear: at the cross and on the cross God the Father and God the Son suffer in different ways. Moltmann explains that when God the Father forsook Jesus, this forsakenness meant that God was handing over His Son, thereby forsaking Himself also. On the other hand Jesus suffers because God the Father has forsaken Him, and although the Father also suffers Jesus suffers from His Godforsakenness. The suffering of the Father is not unto death but is a compassionate suffering arising from his love.

Moltmann's theology of the cross is a radical theology and implies that God is not only at work in suffering and history, but that suffering and history are in God, and occur within Him (Louw, 2000:90). This helps us to understand that God does not reveal His compassion only in the suffering, but that He identifies with the suffering (God's pathos). This identification is simultaneously a definition of the very Being of God, Himself.

The value of Moltmann's theology of the cross exists in the fact that he tries to indicate how God, through the suffering of the Son, truly identifies Himself with the suffering of humankind (Louw, 2000:90).

If suffering touches the very Being of God, the question arises, how does it *affect* the Being of God in other words, in what way? The fact that the very Being of God is affected by suffering and the notion that God Himself suffers has consequences for our understanding of God.

Suffering touches the heart of God-images. As cited in Louw (2012:92) Fretheim acknowledges the importance of our understanding of a God that is vulnerable, and hence the concept of a divine lament in the Old Testament. He explains further that the human cry becomes God's cry and this means that God takes up the human cry and makes it His own. The reasons for God's suffering are threefold:

God suffers because of the people's rejection of Him as the Lord;

- God suffers with the suffering people;
- God suffers *for* people.

Freitheim (see Louw, 2000:92) mentions that the Old Testament reveals God not as one who remains unaffected by the people who reject Him, but as One who is deeply wounded by a broken relationship. However, God absorbed the rejection and affliction of His people and one should not lose touch with the fact that God's grief does not cause Him to be emotionally overwhelmed or embittered by the bombardment of rejection from His people. Instead, His faithfulness and gracious purposes remain constant and undiminished. The salvific will of God has never altered or wavered, but His steadfast love endures forever. Therefore, the understanding is that the 'suffering God' indicates that He does not look at suffering extraneously, but from within God is internally related to the suffering of His people.

In the debate surrounding the theology of the cross, two dynamic perspectives should always be kept in mind and kept together: the salvific meaning of God's identification with human suffering, and the demonstrative and convincing effect of his identification, i.e. to prove His faithfulness. When we start to experience 'God in our suffering' it becomes a pastoral metaphor for consolation and the knowledge that suffering is part of God. This however should always be understood in terms of Christ's reconciliation and mediatory work.

Louw (2000:93) explains that with the above-mentioned in mind God suffers in two ways:

• God suffers in terms of his involvement with his people and because of the humiliation he

experienced on behalf of their misery, affliction and sin. Therefore, his judgment over sin is an indication of his wounded-ness (mercy). God actually suffers because of His faithfulness;

• God suffers in order to forgive and to reconcile and therefore His suffering refers to grace and his mediatory intervention on our behalf.

An important point that should be highlighted is that reconciliation with God has a final, unique and perfect character. Louw (2000:93) explains this as follows: "...faith depends on vicarious suffering. God is suffering, not only with us, but also for us in our place. Suffering is not only inclusive (with us) but, primarily, it is exclusive (for us)."

## 4.6.3 The pastoral dimension in a theologia crucis

In the theology of the cross (theologia crucis) vulnerability, compassion, and reconciliation are of the essence. The argument thus far is based on the fact that the answer to "How?" cannot be separated from the cross of Christ, therefore, the value of a theology of the cross reveals to us God's how in terms of pathos. The passion of God refers to divine authenticity and identity. Louw (2000:98) explains that suffering becomes a characteristic and feature of God's faithfulness to his promises.

An important point in the suffering God and the cross of Christ debate, is that we should understand that a theological hermeneutics of the cross should finally be interpreted in terms of pneumatology (Louw, 2000:98). This means that the Spirit reveals that Christ's suffering and death cannot be separated from divine intervention, identification and involvement. The understanding therefore is that the cross has been disclosed and declared by the Spirit in terms of the resurrection. This is the pneumatological exegesis of the cross: it reveals God's weakness as power.

When we consider the suffering God and the cross of Christ from the pneumatological perspective, God's pathos and human suffering interact in various ways and it may be said that through the Spirit, a theology of the cross becomes the basis for pastoral care to people who suffer.

Iwand (cited in Louw, 2000:99) is one of the few theologians who deal with the pastoral dimension of the cross. He speaks of the cross having a third dimension (not just

reconciliation or dealing with human pride), which is a pastoral dimension. The theology of the cross makes a new relationship with God possible. If we want to understand our own distress, God's compassion, His grace and wrath at the existence of sin, insight and knowledge of the theology of the cross will lead us to a better understanding.

People who are in a crisis and are exposed to despair, anxiety and guilt, need more than just vulnerability and a 'vision about victory', instead they are in need of continuity (security) despite the uncertainty of isolation and the dread of being forsaken and rejected (Louw, 2012:100). It is therefore important that suffering people need continuity, steadfastness and reliability; both the cross and the resurrection portray these needs. Both the cross and the resurrection portray the faithfulness of God, and answer the "how" of God in suffering. It portrays that the "how" of God in suffering is vulnerability because of his faithfulness, which God declares by saying, 'I shall be your God'.

Our understanding then is that behind God's pathos are his faithfulness and his pathos, giving rise to a bright, everlasting hope. In this context, Louw (2000:100) refers to Luther's commentary on Psalm 5:12: "...our whole theology is based on the cross alone. Hope is essentially hoped in the light of the cross, because human hope is crucified hope... In this God is the God of hope and we are saved in hope."

# 4.6.4 The significance of the notion of a crucified God

For pastoral theology and those who suffer, the notion of the Crucified reflects on the question of what significance the theology of the cross may hold for those who suffer from compassion fatigue. This includes the caregiver who has lost his passion, those who are searching for meaning while experiencing a crisis; they who have lost hope owing to the overwhelming situation they have to face daily. Louw (2000:112) explains the significance of the cross as follows:

People who are suffering must know that every person is a sinner and that all are lost as a result of their own guilt and sin. This however should not lead to the notion of a necessary and causal connection (determinism) between sin and suffering.

Atonement is an act of God and is a revelation of His anger ('woundedness') and a demonstration of his love, presence, pathos and solidarity.

In Christ, as the Mediator, God's divinity and humanity are both involved in suffering. We may say this on the grounds of Christ's high-priestly suffering;

this means that God is not 'absent' in suffering, He identifies Himself with our suffering.

The theology of the cross provides hope because it incorporates both Christ's reconciliation work and God's mercy and grace; the death of Christ on the cross means victory over our suffering.

It is very important to understand that the task of and purpose of pastoral care to those who suffer is not to create the illusion that the cross solves the problem of suffering, because the problem by its nature sometimes remains impossible to solve. What is reassuring, however, is that the perspective of a crucified God meets the problem of suffering with voluntary cosuffering and co-vulnerability.

Bauckmann (see Louw, 2000:114) explains that it is the 'suffering within the suffering': the lack of love, the abandonment in suffering that makes it difficult for people sometimes to bear. The theology of the cross shows God's solidarity in suffering in the first place we have become aware of the crucified God's solidarity with all who suffer, and, in consequence, also his followers' identification with the suffering. It does not cause the suffering to disappear but as mentioned, it does overcome the suffering within the suffering. The results of the notion of a crucified and suffering God are threefold (Louw, 2000:114). Although suffering is not eradicated, it is never final. Because of God's vulnerability and woundedness those who suffer can relate to the suffering God. Although there is *pain*, (in the context of this study *compassion fatigue* with the manifestation of all its symptoms), a reliable relationship of trust (faith) always prevails: God is there ("I am your God"). Pastoral care therefore represents this basic form of trust.

However much tension, doubt, despair, anguish and anxiety is generated through suffering, the sufferers can God, even accuse Him, and vent their anger at Him, under all circumstances. It is God's vulnerability and faithfulness that makes the lament an important component of pastoral therapy. It is the crucified God who opens up new avenues and invites sufferers to be honest with Him about their anger and resentment.

Although the problem of suffering exists/remains without any solution in sight, the solidarity does not promote a fatalistic submission but on the contrary, it calls for an active resistance to suffering. Bonhoeffer (in Louw, 2000:114) explains that hope fosters both resistance and surrender. The Christian hope therefore is not about passivity, but about agony (activity) and therefore solidarity includes love's protest against the infliction of suffering on the beloved.

Hughes (1985:49) agrees with these explanations, writing that the theology of the cross affirms that God is unconditional love; and because God is love, divine sensitivity to suffering is at God's very heart one could call it a theology of compassion, in that God suffers both with, and on behalf of men. Hughes (:50) explains that caregivers or people who live beneath the cross of Jesus will experience doubt when they seek to love as He loved or to care as He cared. They are vulnerable to grief-related suffering because they may feel forsaken and God may seem far away when they need support the most. If they understand the theology of the cross, they will experience the divine presence in the midst of pain and need

Our understanding then is that the theology of the cross prevents that divine love from becoming a *romantic* caricature it is not a theology of cheap grace but it urges us to have the courage to grapple with it and discover light in our deepest darkness, God made Christ sin for us and in our place (2 Corinthians 5:21).

# 4.7 Concluding comments

It is mostly impossible to find meaning in suffering. The whys and wherefores of life are elusive and cannot be calculated or figured out as if we were able to understand faultlessly. One does not have to understand everything in order to do something about it, therefore following God in doing what He does, as supremely demonstrated in what Luther calls *theologia-crucis*, is the clear and present path to follow. That is what caregivers do, irrespective of their religion or form of faith. They give of themselves, to ease the suffering of others, and can become so depleted, so fatigued, even worn out, by the -compassion that they give selflessly that they end up needing of care themselves. This study is about affording the same compassion and care to caregivers that they dispense.

The theology of both compassion and the cross may assist caregivers to understand true compassion and to realize that compassion comes at a price. They may feel that no-one understands their exhaustion, and they may experience loneliness The theology of the cross provides hope because it incorporates both Christ's reconciliatory work and God's mercy and grace.

The death of Christ on the cross means victory over our suffering. The theology of the cross

reframes our understanding of God/our God images. In the cross, God's weakness is a sign of His power. Thus God becomes the wounded healer, an image which is significant for pastoral care to the suffering, because it also displays the important theme of God's solidarity with sufferers.

When caregivers experience compassion fatigue or reach a level of utter depletion owing to their compassionate nature and they start to ask questions like, "Why is God doing this?" they should rephrase it as "Where is God in my suffering?" The theology of the cross can assist caregivers in the healing profession who are faced with the suffering, death and dying or eventually their own suffering to understand that God suffers with us; that God is known especially through suffering; that He is a God of passion and compassion. God's compassion is also available for caregivers; he understands what they are going through. The next chapter suggests a possible way to lend pastoral care to the depleted caregiver-

## **CHAPTER 5**

## PASTORAL CARE TO THE DEPLETED CAREGIVER

## 5.1 INTRODUCTION

Chapter 2 presented an overview of the important role caregivers play at various levels of care, and it was seen to be potentially a very rewarding experience but one also laden with various and highly demanding challenges. These challenges can either motivate them or in a worst case scenario demotivate them and cause conditions and situations where caregivers feel overwhelmed by the suffering and pain of patients and clients that they have to witness on a daily basis.

Some caregivers reach a stage where they become emotionally exhausted. The phenomena of compassion fatigue, burnout, and vicarious traumatization were discussed with reference to their respective points of origin and their intensity. The signs and symptoms and possible effects of compassion fatigue were highlighted

As the title of this study suggests, the object of this research is to understand the dynamics of the process in which caregivers develop compassion fatigue, and to offer them appropriate and effective pastoral care. The possibility that people who care for those in need can become so depleted emotionally, psychologically and spiritually that they almost give up on life itself is a crisis that deserves timely prevention. These forms of fatigue break into one's experience of reality and make inroads into one's perseverance and hopefulness. The sheer weight of what causes fatigue can lead to doubt that even God is able to help.

There are no pat, easy answers available for how to deal with a crisis, or in this situation possibly a series of crises (Louw, 2000:143). It can create a false impression that coping mechanisms are about recipes: "When you face this crisis do this and that and then you are sorted out...." In the HIV field caregivers sometimes face patients or clients who are not going to get better no matter how hard they try and even in the midst of the best care, patients die, or those who do not die suffer immensely. The situations and challenges caregivers have to face sometimes have no cure or solution and there is no option but to bear with it.

Chapter 3 examined various types of crises people may experience and how these can influence their lives, thoughts and complete being, and in this chapter we would like to determine how a hermeneutical understanding of crisis management may be most helpful in the pastoral care for HIV caregivers.

Although one cannot change or control what befalls one without warning of impending crisis, one can indeed change one's response and attitude towards such events (Louw, 2012: 144). When people face a crisis, they may survive if their support systems, the support of those around them and the structure of a stable community are available in their time of need. An individual's coping mechanism is linked to the quality of relationships, existing support system, contextuality, and their culture.

In this chapter the focus is on possible interventions that may assist caregivers experiencing compassion fatigue or start to experience symptoms (warning indicators) of compassion fatigue. There is no quick fix to the phenomenon of compassion fatigue but a better understanding of its consequences may provide insight into how a space/place might be created for caregivers to reflect on their experiences.

## **5.2 RETREAT**

It is popularly held that people in crises should get away from their immediate environment. As regards people drained physically, psychologically and spiritually by the very needs that they tried to address, it is imperative to remove them from the impact of the habitat where the cause of the fatigue lies. This is a definite recourse for which a possible model (which for convenience sake could be called a retreat model) is offered tentatively.

In a retreat, caregivers can break away from their normal daily activities to a place and in a space where they are allowed self-reflection, interaction, solitude and guidance in the form of pastoral care. Nouwen (1990:52) supports the 'model' when he shows that creating space for people is not easy in an occupied and preoccupied society. He recommends that the first thing prerequisite is to get an open sympathetic place. Nouwen explains that the world is not changed by a new plan, project or idea it is not even possible to change other people by our convictions, stories, advice and proposals but we can offer a space where people are encouraged to disarm themselves. There they can lay aside their occupations and

preoccupations and listen with attention and care to the voices speaking in their own centre.

Converting hostility to hospitality requires the creation of the friendly empty space where we can reach out to our fellow human beings and invite them into a new relationship. This can be done at a spiritual retreat where empty, depleted people may be replenished. What possible role could pastoral care play at such a venue to assist caregivers in the healing professions?

In the research amongst caregivers and clients, Penman (2012:135) investigated the role that spiritual engagement plays. The purpose of the study was to determine the essence of the lived experience of spirituality and spiritual engagement from the perspective of palliative care clients and caregivers. She wanted to determine why these caregivers and clients engaged in spiritual matters and she discovered that the intention to enhance spirituality increased dramatically, especially in the contemporary western society. This was due to the significant link it had to good health and well-being. People engaged in spirituality due to the benefits that might derive from it. She further explains that the motivations for spiritual engagement were categorized as intrinsic or extrinsic (:135).

Intrinsic motivation is seen as the inborn tendency to engage in one's interest in spirituality and satisfy spiritual needs. This included, "...to have peace and acceptance... to seek healing... to be able to cope... and to also to find positive meaning in illness and suffering" (Penman, 2012:135). She continues to explain that, the extrinsic motivation came from external influences or events that constituted the incentives and consequences to pursue spirituality. This included "to communicate love and concern", "to better care for loved ones", "to build intimate relationships" and to provide comfort to others.

In a summary of the research by Penman, she discovered that spirituality provided many real and potential benefits for those who engage in it (2012:136). It helped people (and as is relevant in this study) to cope. She recommends that it become imperative for nurses and other health care professionals to pay attention to these phenomena. She also discovered that due to spiritual engagement both clients and caregivers had developed new understanding when they were faced with life-limiting conditions. Spiritual engagement made individuals resilient and helped caregivers to cope psycho-socially and emotionally with bereavement, grief, and loss because of their spirituality (:136).

From the conviction of this argument, pastoral care has a huge role to play in assisting

caregivers and working on the spiritual well-being of their souls. That is why the researcher is of the opinion that a spiritual retreat for caregivers will be of great benefit to caregivers (primarily) and in the long run to the people they care for (secondarily) because spiritual engagement nurtures resilience.

## 5.2.1 Retreat as intervention for depleted caregivers

In the place and nature of their work environment, it may happen that caregivers never get an opportunity to debrief certain traumatic incidents, or take time to share with colleagues the difficult issues or challenges they have to face in the line of caring for others. When caring starts to hurt who do you talk or turn to?

Turning to a manager might show signs of weakness or even incompetency, therefore taking caregivers away from their working environment to a place and a space with a relaxing atmosphere, a welcoming and safe environment, will assist them to open up and reflect on their own experiences. They might also be willing to share their experiences and listen to the experiences of other caregivers.

Cahill (2007:24) is a retreat director and she shares how often she heard the similarities in the stories of those on a retreat. In their work things are extremely busy some describe it as feeling they are on a merry-go-round, life is so hectic, "I am always rushing... I have no time for myself anymore or I am out of touch with my feelings" (:24). These expressions give an idea of what caregivers experience and have to get away from escape.

Commitments compete for people's time and energy and may cause them to lose touch with the deepest aspirations of their being and of the Divine Presence (Cahill, 2007:24). Due to the frantic pace of life and number of people who need attention and help, it seems as if life robs people from their sense of purpose and causes them to lose sight of who they are and what they are doing. Cahill uses the analogy of the Disney movie, "The Lion King", where the good king's wicked brother convinces Simba (the king's son and the heir to the throne) that he was responsible for the death of his father. Strangely enough, Simba is driven by guilt and abdicates all responsibility as king. He wanders around in the wilderness trying to make sense out of his life. His father appears to him ,calls him by his name and reminds Simba actually commands him to remember who he is. The encounter with his father motivates Simba to do

what he was called to do.

When one looks at the signs and symptoms caregivers may experience as discussed in chapter three, one realises that each of us experience moments in our lives when we resonate with Simba's forgetting of who we are. The lack of courage to continue with life or the overwhelming amount of suffering that has to be dealt with, creates a longing for a voice to remind us-to live well. Cahill (2007:24) recommends that a retreat, a pause along the road of life provides that opportunity.

A retreat means to withdraw and refers to a time and a place of quiet and solitude in order to focus on our relationships with ourselves, others, the earth and God (Cahill, 2007:24). There the benefits of a retreat problem-solving, personal growth and development may be enjoyed, but the actual focus of a retreat, to renewing the relationship with God, can bear fruit. The researcher would therefore share the opinion that since compassion fatigue may penetrate the spiritual dimension of caregivers by challenging their belief systems ("Who is God?"), the sense and purpose of life, to get away and spend time with God (in a manner of speaking) should benefit caregivers.

Cahill (2007:25; compare also Jud, 1975:61) shows that a retreat holds the following advantages:

- A retreat is a time to remember who we are and who we are becoming;
- Retreats have the ability to awaken a mystery in people especially when their senses have been dulled to the beauty and goodness of life;
- It enables people to discern more clearly the movements of the Spirit and to discover God anew in their life;
- It offers people long periods of extended silence and solitude (this is seen as a "space" where people can be honest with themselves and in touch with the quality of their relationships);
- Directors, or guides are available, who listen to people and assist them in getting to know their own story in more depth;
- Because there is a retreat community, certain commitments are made concerning support, unconditional acceptance, and support for one another. The similarities in the experiences people share create a spiritual community.

The purpose of the retreat is not to deal with the symptoms that are easily visible, but to determine or discover the root cause for these symptoms (Rodrigues, 2009:15). There one can literally take stock of where one is at that moment in one's life. The purpose therefore is to

assist caregivers who experience the warning signs and symptoms as discussed in chapter 3 and who are depleted due to over-caring.

The retreat model of intervention underlines what Nouwen (2010:33) explains: "[s]olitude begins with a time and a place for God and God alone" and "...in solitude we encounter not only God but also our true self."

In a previous chapter it was mentioned that compassion fatigue penetrates the spiritual realm of caregivers to an extent where they start to question the meaning of life, and start to experience a lack of self-confidence loss of purpose, pervasive hopelessness, anger towards God, they question prior religious beliefs, lose faith in a higher power and are-sceptical about religion. Nouwen explains that people who experience these signs need a place and space of solitude where they may experience that solitude is the way in which people grow into a realization that where they are most alone, they are most loved by God.

In that space, one can discover that one's activities become activities done for the other. Caregivers may recognize one another as people who are called by the same God. Therefore, if individuals can find God in their solitude, then it is the same God that calls them together, they can become friends and a community that sustains its members. Nouwen (2010:41) refers to the concept of "...tending our inner garden" and explains that to be calm and quiet by oneself is not the same as sleeping. Contrarily, it means being fully awake and following with close attention every movement going on inside oneself. Such awareness requires the discipline to recognize the longing/need to get up and go again.

Despite the temptation to look elsewhere, you must find what is close at hand. "Tending one's own garden" offers the freedom to stroll in your own inner yard, rake up the leaves, and clear the paths so one can easily find the way to one's heart. It might at first be difficult to move upon unfamiliar terrain but slowly and surely, people will discover an order and a familiarity that deepens the longing to stay at home (:42).

Nouwen calls this our "inner space" and by discovering it with the new confidence, people are able to recapture their own life afresh from within. The inner space is a place where feelings of love and hate, tenderness and pain, forgiveness and greed are separated, strengthened, or reformed; there surfaces the mastery of the gentle hand. Nouwen sees this as the hand of the gardener who carefully makes space for a new plant to grow and who does not pull weeds too

hastily, but only uproots those which may threaten to choke the young life.(:43)

It is in these moments of solitude that compassionate solidarity grows may be discovered as people grow closer to each other. Nouwen stresses further that people need to understand that solitude is essential for community life, although when we pray alone, study, read, write, or simply spend quiet time away from the places where we regularly interact with others, we are in fact participating fully in the growth of community (Nouwen, 2010:44).

The role therefore of the pastoral caregiver is to assist, guide, and empower those who suffer from compassion fatigue. The researcher is of the opinion that caregivers must be empowered and the retreat-allows them a space and a place to reflect. In resting and doing soul-searching it can empower caregivers with coping skills. Reframing their paradigm, rediscovering why they are committed to caring for the suffering of others demands such an opportunity for being succoured for coping anew with the many challenges they are required to face.

It has to be understood that if caregivers have lost their connection with the people they care for, they have lost the connection with why they are in the caring profession. Reflecting on what Nouwen explained the researcher is of the opinion that a retreat might therefore prove viable as effective intervention or engagement to assist with that compassionate reconnection to oneself and to others.

# 5.3 EMPOWERING CAREGIVERS WITH COPING SKILLS

In the previous section the discussion focused on how to help depleted caregivers to deal with compassion fatigue. The idea is not just to help them to work through their own pain and suffering in order to be healed, but also to assist other caregivers who are not yet depleted, to prevent or lower the risk of developing compassion fatigue. In this process of helping and journeying with caregivers the practical theological purpose is to contribute to the healing of life from a Christian spiritual point of view.

Louw (2008:12) explains that suffering tests the quality of life within the core of person's being. Whether caregivers succeed depends upon whether they have an address to take their needs. This address could become the living and suffering God. The following section will focus therefore on pointing them to the address (whether they are depleted or not yet fully so)

of the suffering and compassionate God.

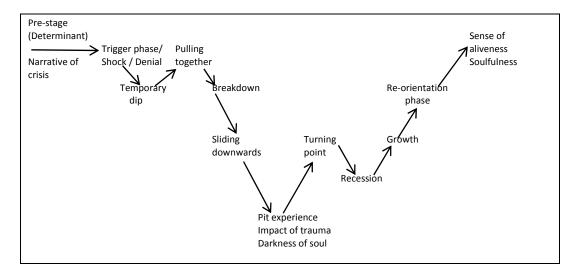
As mentioned previously, pastoral care should also empower people, and knowledge is power. With reference to what was reported on a retreat as a viable intervention for depleted caregivers, such a venue is the golden opportunity to teach caregivers some coping skills which will empower them to experience compassion satisfaction and will create awareness to be alert for warning signs of burnout, compassion fatigue or vicarious traumatisation.

When people face a crisis, they may survive it only if their support systems, the support of those around them and the structure of a stable community are available to them in their time of need. An individual's coping mechanism is linked directly to the quality of relationships, existing support system, context and the culture—in.

# 5.3.1 Stages of crisis development

During a retreat, caregivers can be informed and empowered to recognise a crisis pro-actively . Crises have different stages of development. In figure 5, Louw (2012:149) shows the flow of a crisis and crisis behaviour; also the different responses to the impact of crises and various dispositions:

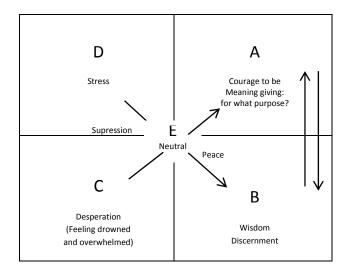
Figure 5.1 Graphic depiction of The flow of a crisis and its various stages



The figure provides a perspective of how people position themselves in various crises and the position they choose determine their behaviour and actions. No one can change what happens

to you, but you can choose how to respond. The responses are discussed below, with reference to next diagram that highlights the way people position themselves (Louw, 2012:150).

Figure 5.2: Positioning in crises



#### Position A

When someone positions himself (A), he is between growth (re-orientation) and action (responsibility). Although he is suffering or experiencing compassion fatigue, he shows the courage to discover new possibilities and purpose. This relates to the human quest for meaning and the action of goal setting. Caregivers may take in this position and search for learning or growth opportunities. Instead of asking is why this is happening the question should rather be what we can learn from this, or how we can protect ourself or others against it; alternatively, how we can care better for ourselves or our patients.

The suffering is still there and patients are still sick and maybe dying but despite the situation, growth is possible. One would like to believe that when someone is still able to see opportunities of growth, purpose and can choose direction one discovers meaning and purpose.

### Position B

This position indicates one's ability to discern between what is possible and what is not. Maybe caregivers are not in a position to change the circumstances of their patients and can do only so much with the skills and resources available to them, thus this position lies between growth (re-orientation) and acceptance. They need to accept the things they cannot change.

#### Position C

People in this position experience desperation where depression is the overwhelming emotional condition. Their human identity has been affected to such an extent that they reach a point of "cannot anymore" and can suffer feelings of nothingness, incompetency, low morale (Figley, 2002:7). A caregiver might feel that the crisis of caring is overwhelming and end up feeling too much compassion. There is a willingness to keep on rendering care to those in need, but the person cannot carry on due to overexposure to pain and suffering.

#### Position D

People in this position endure despite experiencing tension and stress. It also indicates multiplication of coping mechanisms without any meaningful outcome. This position is between the polarities of action and regression/deterioration, therefore this is a position of survival and worry. If people do not have the skills to attempt alternative routes they will try to do more of the same and get the same results over and over again.

#### Position E

This position represents a neutral stance where someone chooses either to be content (peace) or suppressed (creating the impression that one is coping). People choose the positions they are in and sometimes it is difficult to shift/change position because the skills or agencies to do so are lacking.

With the above explanation in mind, the positions people choose and the attitudes and aptitudes they hold might determine how long they will experience their situation as a crisis.

## 5.3.2 Compassion fatigue as crisis

Louw (2012:144) is of the opinion that a description of the hermeneutics of crisis management is not an attempt to identify the possible cause of the crisis; nor does it propose an explanatory model of cause and effect. One might query the value of understanding the cause of the crisis, not knowing how this will make the person in crisis feel better, or handle the crisis better. Understanding what is happening in the crisis with references to the networking that is taking place has more value, because people may discover connections between various bipolarities, the responses and attitudes. During the retreat, participants can be assisted and guided to gain a better understanding of the networking that is taking place and that God is ever-present.

The hermeneutics of crisis management help people and in this case, may assist HIV caregivers to reflect on existing coping mechanisms when they are opposed with the suffering and death of clients or work related issues. It indicates further how a "soul" operates when challenged by various crises; and it reveals the quality of our being-functions, assisting us to discover soulfulness (*cura animarum*) despite circumstances of hopelessness, helplessness and depression (Louw, 2012:144).

As noted by Figley (2002:7), caregivers who suffer from compassion fatigue may struggle (for example) on a spiritual level (with, for instance hopelessness) and who are questioning the meaning of life, the purpose of life (even their own) and querying their prior religious beliefs. This corresponds with what Louw (2012:144) argues: that the attempt to find meaning refers to direction a movement forward and an expectation of a significant future.

The researcher interprets the quest for meaning as something positive because at least people are trying to understand, to process what is happening almost as if when they understanding the meaning it will redirect their life. I believe as long as people are asking and searching for meaning they have not lost all hope and purpose.

Louw (2012:144) posited that meaning is not "something" (sometimes there is no meaning) but it is a pathway one may take toward a sense of purposefulness, significance, and alignment. When people understand this their questions will change from "why the suffering/pain" to "for what purpose".

## 5.3.3 Existential realities/threats in a crisis

The depleted caregivers who have lost their passion to care or who are left totally drained by the overwhelming impact of HIV and AIDS on their client/patients and families may wonder about the meaning and the purpose of all the suffering they have to face on a daily basis. As pastoral caregivers their role should be to assist people to ask not right or wrong questions, but appropriate questions, when faced with crises or a search for meaning.

The "for what purpose" question, as Louw (2012:144) explains it, can be posed only once people have become aware of the most basic existential issues that **threaten** the quest for meaning. He explains that meaning can be experienced only when the basic existential realities and needs are addressed and connected to spiritual expectations and convictions, in such a way that hope, joy and gratitude set in.

The existential realities/threats can be explained as follows (Louw, 2012:82):

### **Anxiety**

Caregivers to HIV and AIDS patients are bound to lose patients. The overwhelming effects of working in a caring environment and especially when a caregiver begins to experience compassion fatigue, can easily be interpreted by management or supervisors as incompetence or laziness. A caregiver may begin to think, "What will/do my colleagues think of me?" and these thoughts are bound to cause anxiety.

Anxiety is closely related to loss and isolation (fear of being rejected and isolated) the dynamics of human relationships. Intimacy and acceptance, the need to be accepted by others for who we are without the fear of rejection and preconditions, are considered our basic existential needs. One can just imagine the situation of a caregiver overwhelmed by his or her caregiving and disclosing this to others how do you explain that you are tired of caring? Anxiety may cause caregivers to keep their real feelings secret and so be forced them to live artificial lives in a state of denial or confusion because they do not understand what is happening to them.

#### Guilt

Guilt refers to our conscience and guilt feelings how guilt affects the ego and infiltrates the self-esteem and subjective, emotional reactions. One can again imagine that when a caregiver loses a patient or client he may struggle with questions like "Did I do my best?" "Could we have done more or something different?" Caregivers may have guilt feelings about not having spent enough time with patients or clients due to their workload.

## Despair

When one looks at the signs and symptoms of compassion fatigue, like decreased self-esteem, low morale, low motivation (Figley, 2002:7) then this is an expression of despair that derives from doubt. The person sees no alternatives and as Louw (2012:145) puts it, that person is in the *cul de sac* of the human soul.

## Helplessness and vulnerability

When people reach a stage where they do not know which way to turn, or have tried everything possible, they start to feel the existential threat of helplessness. Helplessness is an indication that someone has become dysfunctional he became stuck in a situation (Louw, 2012:145) and this helplessness creates the functional crisis of desperation. The impact on the caregiver's ego is one of feeling drained/depleted, which in turn creates existential frustration.

Helplessness can deteriorate and mutate to anger that has is turned inwards (Louw, 2012:145) the depleted person turns on himself.

## Disillusionment, frustration, and anger

People become angry or express anger due to unfulfilled needs, disappointment due to expectations that cannot realize, and an awareness of failure due to the lack of appropriate coping skills (Louw, 2012:145). Crises can cause people to make a shocking discovery of being incompetent to deal with the crisis.

## 5.4 PASTORAL CARE TO CAREGIVERS IN CRISIS

The existential threats of anxiety, guilt, despair, helplessness and anger raise the question: What should a meaningful alternative and a constructive attitude look like to cope with these existential realities? Louw (2012:145) explains that if we consider these existential threats and call them *the darkness of the soul* or *the shadows of the soulfulness*, then alternatives may be called the brightness or fullness of the soul. In the context of this study, one may suppose that the obverse of compassion fatigue would be compassion rejuvenation.

Alternatively, if the negative and grim circumstances set out above lead to compassion fatigue and frustration, a positive upturn would logically boil down to compassion satisfaction. The ideal situation would be for caregivers to experience soulfulness, but the existential threats are always lurking in the shadows. They can be uncovered by the horizon of meaning and different perspectives on anxiety, guilt despair, helplessness, and anger.

Louw (2012:145) identifies these perspectives or dimensions of meaningfulness as intimacy (love), freedom (liberation), hope, compassion, and gratitude. The following diagram portrays the horizon of meaning that may help caregivers who suffer from compassion fatigue as well as those who are not suffering yet but are at risk, to discover soulfulness and existential brightness, despite the threatening shadows:

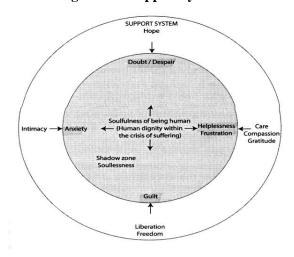


Figure 5.3: Support system

Louw (2012:146) explains the figure as follows: people will experience existential brightness in the form of enjoyment and gratitude due to the fact that rejection/isolation is displaced by

intimacy, guilt by freedom, despair by hope and helplessness by care. They are therefore opposites of each other while the threats cause the soul to end up in the darkness, the existential brightness leads to soulfulness.

In pastoral care the role of the caregiver is to meet people where they are and journey with them to a place of soulfulness, from the darkness of soul to the brightness of soulfulness (Louw, 2012:75). The displacement of the existential threats has a positive impact on the lives of those who suffer and search for meaning. These positives are now discussed (compare Louw, 2012:146).

# **5.4.1** Anxiety replaced by intimacy (unconditional love)

The basic need of every person is to be accepted unconditionally and without the fear of being rejected or isolated. Where such anxiety reflects a sense of impending loss, intimacy represents acceptance, security and a feeling of belonging, and so fills a space of grace and unconditional love. In the Christian faith, the ethos of sacrificial love plays an important role in creating an existential experience of acceptance and exposure to joy and happiness. The theology of the cross as discussed above proclaims that Christ sacrificed Himself out of unconditional love; the challenge is therefore that our love should also be unconditional.

The ideal situation, the brightness-moment will be when caregivers can come to the understanding that God loves them unconditionally, no matter what crisis they are facing and that He accepts them just as they are. Just as they have the need to be accepted, patients and those who suffer also needs assurance that God has not forgotten them, and a space for intimacy evolves when people become aware of God's unconditional love and start to live in that love.

# 5.4.2 Guilt replaced by freedom (liberation, peace, and reconciliation)

Meaning has to do with an experience of liberation, freedom, forgiveness and reconciliation (Louw, 2012:146). To change one's position from being a victim of the past sets one's soul free. Even when caregivers struggle with guilt feelings born from a sense of not doing their best or failing their patients, an awareness of God's forgiveness together with self-forgiveness

will lead them to experience freedom and inner peace.

## 5.4.3 Despair replaced by hope

Compassion fatigue may cause caregivers to lose hope and despair robs a person's soul of its future, without which, life becomes unbearable. Hope, contrarily, gives purpose but only if one possesses the basic skills of creativity and imagination. No matter how dark the situation, if one can find opportunities creatively in the midst of the suffering and depletion it gives new purpose and direction.

# 5.4.4 Helplessness replaced by compassion (care)

A situation where a caregiver who bears other people's burdens, needs to be cared for or even, 'carried' may sound strange. Caregivers are not supposed to give in so people think but as was shown, very often caregivers shoulder a very heavy burden, and when they are depleted they need the same tender, restoring care that they lavish so selflessly on others in need of care. The fact that they give care does not elevate them above a similar need for care, compassion and counselling. In the time of their own helplessness, caregivers also need a 'soul guard' or a soul-mentor to be their support system, who will journey with them with compassion and understanding. It is important therefore for caregivers to surround themselves with others (like colleagues, pastoral caregivers, family, the church) to support them in turn during difficult times.

The church or the community of believers can play a tremendous role in sustaining those who virtually act on behalf of the church in caregiving. With the *koinonia* of the church, a space of mutual care can be established by means of empathy and sympathy. We can therefore say that the quality of compassion of the fellowship enhances or promotes soulfulness.

# 5.4.5 Anger replaced by a sacramental understanding of life

People experience anger and frustration when their needs are not met, but when life is viewed as a gift, gratitude sets in. Hence, when life is viewed from a sacramental understanding of all its elements your mind, your body, your sexuality, marriage, family, friends even the patients you have to care for, everything points to grace. The element of grace should become the channel through which the fruits of the Spirit are manifested in such a way that people

become aware of the glowing presence of the living and loving God the God of grace and reconciliation.

When people can experience existential brightness there is not just healing of the soul (*cura animaru*) but the very healing of life itself (*cura vitae*).

# 5.5 GOD-IMAGES THAT PEOPLE UPHOLD IN TIME OF CRISIS

Inappropriate God-images may intensify the crisis of compassion fatigue therefore it is the role of the pastor to assist caregivers and guide them to more appropriate God-images.

As the literature indicates that compassion fatigue and burnout differ in terms of degree and cause, those who suffer from burnout may shift their position by resigning their jobs. People in the caregiving profession will and do shift, but due to their compassionate nature a shift to another caregiving profession nearly always has the same outcome. The shift may be to where exposure to suffering and pain is not so severe, but this does not guarantee immunity nor protection against compassion fatigue. As long as caregivers are in an environment of exposure to the pain and suffering of fellow human beings, the possibility of burnout and/or compassion fatigue remains.

As discussed, people assume various positions in times of crisis, a crisis might expand to affect the spiritual realm as well (Louw, 2012:158). Figley (2002:7) describes these symptoms: questioning the meaning of life, questioning prior religious beliefs, loss of faith in a higher power and purpose in life. Louw (2012:158) explains that it invades spirituality owing to the interconnection between self-understanding and different God Images.

A question that might come to mind is "Is God the cause of this suffering, and is He now punishing us?" This and other questions of the same ilk cast God in a very negative mould, and Louw (2012:159) proposes the following four God-images in crisis behaviour:

#### God as Lord

From a spiritual understanding, people may still experience God as being in control of everything and being guided by His wisdom. Our faith makes it possible to rely on His faithfulness despite the crises around us. Caregivers who understand that, know that God

loves them unconditionally and remains faithful.

### God as a soulmate, partner for life

The theology of the cross reveals that God is part of our human suffering and that He has identified Himself with the suffering of people. The cross is the symbol of the woundedness and the vulnerability of God. The crisis does not necessarily go away, nor need a solution be readily at hand, but God indeed offers salvation (grace) amidst our suffering and predicament. Here caregivers may rely on God's promise, "I will be your God."

The theology of the cross therefore helps to reshape the God-images of those that feel forsaken, alone and depleted because it points out that God is not distant, but suffering along with suffering caregivers.

#### God as parent

This mage of God evokes a caring parent who demonstrates compassion and nurtures one in suffering. With God as a father or mother, sufferers are taken up in His embrace.

#### God as judge

God is a God of justice, responding to injustice and evil. He deals with guilt in a fair and just manner. If one understands the omnipotence of God only in terms of a brutal manifestation of power (force) then God will always be seen as the oppressor in the stories of suffering. Therefore, when pastoral caregivers can journey with people/caregivers, helping to change their understanding of God's power and showing them God's power from the perspective of woundedness and vulnerability, new perspectives emerge.

This is possible due to the revelation of God's identification with our suffering through Christ. If this paradigm shift takes place, God is no longer the instigator, but the covenantal Partner in Life and one's Soulmate in suffering; this allows sufferers to experience care, compassion and consolation.

## 5.6 ASSISTANCE TO CAREGIVERS

As has been shown, in their compassionate caring for others, caregivers' reserves become depleted, leaving them too exhausted to continue bearing the burdens of those whom they have to help. The crucial issue is assisting fatigued caregivers to rediscover meaning and purpose in their crises.

Ferrari, Jason and Salina (1995:99) report that in their a study-amongst pastoral caregivers rendering care to people living with HIV and AIDS, their theological training about the understanding of death facilitated their coping with impending client death. The researcher is therefore of the opinion that all caregivers should have the opportunity to attend workshops or retreats, featuring discussions and teaching concerning suffering death and dying from a theological perspective.

# **5.6.1** The shifting of positions

In order to experience healing and change it is important that one shifts one's position and this is only possible when the person's emotional stance becomes stable (Louw, 2012:156). Sufficient ego strength and cognitive and conative control are required to reflect on the situation of pain, suffering and disorientation.

With reference to Figure 5.4 below, a person may shift from position D (stress) to position B (wisdom, discernment) to A. Here the shift is from stress to discernment and then to courage.

D Α Stress Courage to be Meaning giving: for what purpose? Supression Ε Neutral Peace C В Wisdom (Feeling drowned and overwhelmed) Discernment Or

Figure 5.4 positions people take in in times of crisis POSITIONING IN CRISES

The person may shift from position C (desperation, feeling overwhelmed) to A (courage to be, meaning-giving, seeking purpose) or B (wisdom and discernment). The shift is from

desperation to courage and then to discernment. The basic assumption of, and the motivation behind this model of healing is threefold (Louw, 2012:86).

People should see crises as opportunities for change, in other words, when someone is overwhelmed or stressed, or experiencing a crisis and the search for meaning and the fostering of a spiritual identity, he or she can review the quality of the choices made during/within painful conditions of human suffering.

Van Dyk (2012:330) and Louw (2012:85) consider the logotherapy of Viktor Frankl (a survivor of the Nazi concentration camps) very useful. The shifting of positions can open up new possibilities despite the reality of suffering or compassion fatigue.

As cited in Van Dyk (2012:330), Frankl held the opinion that meaning cannot be created or invented (it is not something as previously explained by Louw), it can only be found and discovered. Therefore, our role as pastoral caregivers is to journey with and to facilitate depleted caregivers and assist them to discover and find meaning. Every single person's search for meaning and purpose will be different and unique and will depend largely on their personality and religious framework. According to Frankl (in Van Dyk, 2012: 330), the search for the meaning of life depends largely on the philosophy of existentialism.

The understanding of existentialism is that any significant value in the universe has to come from within oneself. However, this should not be a search for some kind of objective truth about the meaning of life or hours spent in on meditation on the ultimate reality of life.

Frankl (in Van Dyk, 2012:330) explains that pondering around about the "...hard to make out" universe is not only frustrating but also useless. A more practical and rewarding way to discover meaning in life is necessary and the following is suggested:

- Do something;
- Experience something or have an encounter with someone; and
- Consider the attitude you adopt towards unavoidable suffering.

What Frankl wants to convey is that life does not become meaningful when someone is informed what it is supposed to be, or when the correct or definite answer to a question is discovered. Caregivers may wonder why bad things such as HIV and AIDS happen to people, therefore it is important to understand that meaning is found by doing and experiencing meaningful things. However, this is possible only when one adopts a positive stance towards

life in general, specifically suffering (Louw, 2007:134).

Frankl's understanding is that people are free to choose; although they may not always be able to avoid negative circumstances and suffering, they are free to choose how they are going to respond to those circumstances. The moment people understand this concept they may start to work actively towards a meaningful life, even in the midst of death and dehumanization. Caregivers who find themselves in a position of being overwhelmed by the care they offered to others and suffer themselves from compassion fatigue, or who are just overwhelmed by the pain and suffering of others still have a choice how they are going to react to these circumstances.

Diagram 5.4 in Louw (2012:86) illustrates the possible shifts (with reflection on Frankl's logotherapy) that people can make in order to discover meaning, new purpose, and direction.

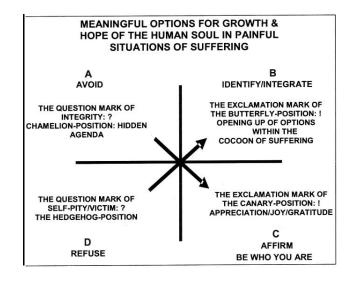


Diagram 5.5: Meaningful options for growth and hope

Louw tells us that Frankl experienced the worst kind of suffering and humiliation in a Nazi concentration camp. He had an opportunity to escape from these circumstances but turned back to look after a dying friend. In that moment, Frankl sacrificed his freedom for a dying fellow human and in the process of taking that decision he created (in his being-function and as consequences of decision) a space of dignity within the realm of death. Frankl did something meaningful because he had an encounter with a dying friend and in this highly compassionate and meaningful situation, he unknowingly created for himself *identity* and instilled *meaning* in his own life.

With reference to the diagram, Frankl shifted his position from self-pity and the role of a victim (the so-called Hedgehog position) to opening up new options (to which Louw refers as the Butterfly position); from the hidden personal agenda (Chameleon position) to a yellow bright position of appreciation/gratitude (the 'Canary' position). Frankl embraced life despite the terrible reality of the smoking crematorium ovens of the concentration camp (Louw, 2012:85).

In the Pastoral care of meted out to caregivers, they should get assistance to make that choice, to 'shift' them, so that despite the suffering of patients, despite the overwhelming impact of HIV and AIDS on caregiving in general, the reality of possible burnout and compassion fatigue, they still have a choice on the position they are going to take.

Louw (2012:85) explains the positions referred to above in detail:

<u>Position A:</u> *chameleon-position:* the attempt where one hides your true intentions in an effort to withdraw or get away from the challenges that suffering bestows on you. When someone who is taken up in caregiving avoids or ignores this threat of suffering or compassion fatigue, life becomes superficial for him.

<u>Position B:</u> butterfly position: caregivers may assess their situation, accept what they cannot change and resolve to change what they can, by-setting new goals. They need to identify (to make peace) with their own suffering by declaring: "This is my suffering and my situation", and use the limitation set by loss (to which Louw refers as "...a pupa in a cocoon") to change their attitude. Establishing new goals or objectives opens up amazing options i.e. to become a butterfly and one can begin to live differently (almost with defiance against researcher) within the worst conditions. Therefore, if one can integrate the pain of suffering into one's being, that will serve as the first step towards meaningful change.

Van Dyk (2012:430) agrees with this perspective, saying that caregivers should realize and accept that in caring for AIDS patients the emphasis is on **caring** and **not curing**. They must learn not to feel or take responsibility for things they cannot change. Skovholt (cited by Van Dyk, 2012:430) advises that caregivers should ensure that they have both long- and short-term goals in their work with clients. HIV and AIDS sufferers can be guided and assisted to follow an alternative lifestyle that can extend their lifespan significantly; those that are terminally ill can be succoured and cared for to live dignified lives in the time that they may have. In this

manner, caregivers can indeed feel the rewards in the knowledge that there was progress along the way of achieving both short- and long-term goals.

<u>Position C</u>: *canary position*: reflects on the caregivers' being-function, in other words exactly who the person/caregiver is. The example of the canary describes his being a canary can sing its bright tune even when the rain is pouring down. In other words, regardless of what happens, the canary remains true to his being to be a canary and not become something else.

True compassion is an articulation of the caregiver's true being –by exercising compassion he or she emulates God, the compassionate. It does not serve only as indication of sensitivity (Louw, 2008:281), but may be described as a pneumatological witness of the charisma of the Holy Spirit in them. It describes the virtue of unconditional love and the willingness to become involved. Therefore empathy is part and parcel of compassion the capacity to identify with, to understand and respond to someone else's frame of reference.

Even when fully aware of the cost of caring, as humanbeigns we cannot deny compassion and empathy as a part of our being-functions. Our being-functions constitute and affirm our identity as human beings as the canary's being-functions affirm its being. Our human identity can thus be related to the metaphor of the olive tree as our eschatological identity affirms our ethos/being functions/fruits of the spirit (Louw, 2012:86). In other words, regardless of compassion fatigue as a state of being, caregivers function in compassion and empathy despite the prevailing situation.

While acknowledging these being-functions, there remains a space in which to shift one's positioning. Translated to Christian spiritual language it means that one does not have to 'have' compassion, one becomes compassion and reflects the compassion of Christ.

<u>Position D</u>: the *hedgehog position* refers to the person (metaphorically) bundling himself up as a defence, shutting himself off and refusing to face the challenges life throws at him. This generates a passive mood and leads to self-pity and refusal to do something about the situation or to make an active choice.

A meaningful option (with reference to the diagram) in a very difficult situation (such as burnout, compassion fatigue, vicarious traumatization in the case of caregivers) is to move from  $\bf A$  to  $\bf C$  (Louw, 2012:86). This would mean to progress from the chameleon position (avoidance/denial) to the canary position (acknowledge who you are and do accordingly), or

to shift from **D** to **C** from being the victim (of self-pity and refusal to identify) to a search for new options. The crisis/crises do not go away but the intention is to use the crisis as the paradigm to develop a different perspective/s on the same situation.

Lombardo (2011:4) advocates the praxis (and which the researcher supports) that the pastoral care/chaplaincy department (for example in HIV and AIDS care institutions) should ideally include a suitable variation of services to include the support of the nursing staff and other caregiving positions. Although Lombardo sees the goal of pastoral care as meeting the needs of patients and families, the staff at healthcare or home based facilities must not be left out and they must also get pastoral assistance. Supportive activities would include facilitating sessions where caregivers may reflect/reminisce during times of loss or death; leading memorial services; offering prayer and comfort for patients, families and caregivers; and providing spiritual help through individual counselling and group programmes.

The researcher feels that when caregivers are empowered by the coping skills above, or obtain a better understanding of certain concepts and perspectives and God's position in suffering they can become aware that God is present even when they suffer within their suffering. This realisation might afford a sense of aliveness, soulfulness, and compassion satisfaction.

# 5.6.2 Compassion satisfaction

In order to do justice to the research problem, an understanding is necessary of what an ideal situation in caregiving should look like. The opposite of compassion fatigue and its cohorts is compassion satisfaction. Compassion satisfaction may be expected when caregivers get the necessary attention and adequate support, and those who suffer compassion fatigue are pastorally equipped to shift their positions.

It was shown that caring can cause caregivers to suffer from compassion fatigue and strategies to assist caregivers to experience soulfulness were touched upon. Although the purpose/aim of the study is not to explore compassion satisfaction, it is logical that compassion satisfaction would be the ideal aim to achieve in pastoral care of caregivers who are at the end of their abilities resources. If depleted caregivers who have lost the joy for what they are doing towards the welfare of people in need can be restored, or turned into professional satisfaction, then giant strides would have been made. Aptly then Figley (2002:107) describes compassion

satisfaction (as the logical opposite to compassion fatigue) as the satisfaction the caregiver/helper experiences due to helping others, and it plays a vital role in the equation of human services.

Figley (2002:107) further explains that if trauma should challenge control thereby causing psychological distress, the question arises why people who work around trauma are still doing well. The notion of the sustaining positive resources would be a contributing factor. To understand the negative *cost of caring* it is necessary to understand the credits or dividends that come from caring.

Hudson (1999:88) explains that compassionate caring has a cost and that caregivers should take care of themselves in order to experience compassion satisfaction. The researcher is of the opinion that if caregivers were exposed to a personal retreat and learn coping skills they will be enabled to care for themselves in a healthier way.

Anderson (2003:96) explains how important it is for caregivers and spiritual caregivers who take care of others to take care of themselves, especially those who are in the frontline of meeting human needs. He refers to taking care of self as spiritual fitness and explains that human need is an insatiable and unforgiving slave master, as many caregivers who devoted their lives to a ministry of caregiving have found. These caregivers sometimes have to contend with the despair of never being able to satisfy the demand upon a pastoral caregiver and be recognised as adequate for this task.

There is also a growing sense of spiritual inadequacy, as if the one who was called has disappeared into the calling itself. Pastoral caregivers try to rectify this situation by trying to do more and literally throwing himself or herself even more into the work of the ministry.

The whole situation becomes a vicious circle and it seems as if the demands of the ministry have produced a sense of inadequacy, which in turn carries an overtone of spiritual weakness. Some turn to God in desperation, seeking some relief or a way to escape at least, or if not, renewal. If no solution or relief is found it happens that people immerse themselves deeper into the ministry. So the vicious circle continues and, now and then, someone might intervene with a common-sense question: "Don't you think you should take better care of yourself before it is too late?"

# 5.6.3 A practical theology of self-care

In his explanation of a practical theology of self-care Anderson (2003:99) feels that pastoral caregivers and caregivers in general suffer from burnout or compassion fatigue due to a lack of spiritual fitness. It results from a disconnection between the inner life of the self and the social and physical boundaries and limits of a situation where one seeks to meet the demands placed on oneself.

Anderson defines spiritual fitness as the result of practicing a spiritual ecology of holistic self-care expressed in a ministry of caring for other. As cited in Anderson (2003:99) Moore speaks about the growing concern for a spirituality of the inner life and explains that when your soul is neglected, the neglect and its results do not just go away. It surfaces symptomatically as obsessions, addictions, violence, and loss of meaning. Caregivers therefore owe it to themselves to recoup, to replenish what has been poured out continuously, to regain the spiritual fitness so necessary in the stressful life of caring for others. It is in this context that the retreat presents as a possible means where a practical theology of self-care can be realised.

Moore then argues (Anderson, 2003:99) that the root problem is that modern man has mostly lost wisdom about the soul, or even the interest in its preservation. That is why there is a need to teach and help caregivers how to take care not just of their physical selves but of their souls. This is an on-going process of nurturing, and besides attending a retreat, it is important that they take care of themselves. They need to make sure they stay connected to their own inner core of selfhood, to other persons as "soul-mates" and to God as the source of personal and spiritual existence.

Anderson suggests a few practical ways by which caregivers may nourish their inner self and by doing so, become spiritually fit:

#### • Nourishing care for caregivers

Many caregivers lack the kind of nourishing love which they give to others. Although people may meditate on the Scriptures to remind them of God's love for them they need more. Caregivers also need and must cultivate relationships in which they are recipients of the kind of love that they provide to others.

Needing the tangible love of others should not be regarded as a sign of weakness on the side

of caregivers to need the love of others in tangible ways. As McMurray (in Anderson, 2003:107) explains, the inner self are nourished because we need each other, "I need you to be myself." The need described in these words is for a fully positive personal relation where we trust one another and because of this, we can think, feel and act together.

### • Unburdening the inner life of the self

Caregivers can buckle under burdens that are unnecessary even the strongest can bend therefore it is important to understand that spiritual fitness is not determined by how heavy a burden may be borne in life, but how well caregivers bear the burdens that are necessary and how easily they let go of those that are not.

#### • Bearing the right burden

Anderson explains that a self without a burden is immature and even irresponsible, since there are burdens that can be borne only by individuals and burdens that can be borne only in being yoked together. In Galatians 6, the Apostle Paul speaks about the importance of bearing one another's burdens and by doing so the law of Christ is satisfied. He also mentions that we each have our own load to carry. By bearing each other's burdens, we acknowledge to ourselves and to others that there are burdens that simply cannot be borne alone. On the other hand, there are burdens it seems that no else can bear for us.

As cited in Anderson (2003:108) Dietrich Bonhoeffer always reminded his students in spiritual care that if everything is subjected to spiritual care they may wind up with a lack of self-understanding. He saw the goal of pastoral or spiritual care as leading people along on their own personal struggle in order to reach a point where they can experience a breakthrough on their own. If people are too dependent on caregivers their own experience never matures and they abandon the attempts too easily.

A good example of this is seen when the caregiver assists the patient to take his medication or explains how to administer it, but it is the patient's responsibility to take his or her medication. Sometimes caregivers blame themselves when, for example, a patient did not take his or her medication.

#### • Letting God bear the burden of life

When caregivers end up overburdened in life they might be under the impression that they can control their lives. This is what was mentioned: they try to do more, work harder, walk another extra mile hoping that things will work out then, or I will feel better. Anderson explains that this delusion is exposed by Jesus' rhetorical question in Luke 12:25, 26, when He asks, "Can any of you by worrying add a single hour to your span of life? If then you are not able to do so small a thing as that why do you worry about the rest?" Caregivers need to understand that even the lightest burden will break them if it is taken-up for the wrong reason. There are things that can be changed, and there are things that we need to leave to God.

It might be advisable according to Anderson (2003:108) that when caregivers feel overburdened, depleted they start asking themselves why they are carrying the burden of life at all, and not which burdens are the right ones. The burdens that are borne by the power of faith and hope are the burdens of the sower who has no control over the harvest.

Therefore, spiritual fitness is not the ability to carry heavy burdens but to have the gift of faith and the vision of hope by which every burden becomes a seed sown into the soil which we as caregivers cultivate and water, but for which God alone can bring the harvest. Caregivers should try rather to discover which burdens are the ones that cannot be carried alone. The strength and capacity to carry your own burdens or to help someone else, results from proper nourishment and mutual care. According to Anderson, Bonhoeffer always encouraged his students to make sure that they themselves had relationships in which they received the care they offer to others.

It is therefore important that those who care for the soul have someone to care for their soul.

#### • Reconnecting the inner life of the self

Malnutrition, overburdening, and consequently powerlessness are the results of a soul disconnected from its own source. As long as caregivers think that they are able to save themselves they have made their constructed personality almost like God. Sometimes we cannot help ourselves and we need help; we need guidance; and we need to get to a place and space where we can tend our inner garden, as Nouwen puts it. So many caregivers have become disconnected with themselves but they continue to help without success; or they may succeed, but struggle with emptiness inside because the inner self has become disconnected from its own source.

Attention to these areas may result in compassion satisfaction. The researcher is therefore of the opinion that the few pointers Anderson offers can only truly be understood if this is built into a retreat setting. People need space, solitude to reflect on their lives and assistance toward understanding what is happening to them. Hudson (1999:87) explains that to prevent compassion fatigue or experience compassion satisfaction, it is important to pay attention to the following areas:

Caregivers should be compassionate neighbours to themselves: Hudson agrees with Anderson that Christ-followers who consider the challenge of the gospel having compassion for others often neglect to care for themselves. They sometimes fear to do anything that looks selfish and are always putting the needs of others first and not adequately caring for themselves adequately; these are prime candidates for compassion fatigue. He stresses that if we can learn to be a Good Samaritan to ourselves we can be a Good Samaritan to others.

**Take care of your body:** Caring for others uses up a great deal of physical and mental energy. If these resources are not replenished caregivers run the risk of compassion fatigue. We will be of no use to fulfil our God-given callings to be compassionate human beings if our bodies do not received the necessary care it deserves. We should listen to our bodies, relax, exercise, and nourish them.

**Do what you enjoy**: most people have hobbies or favourite things that they do in their spare time, whether working in the garden or doing sport or listening to music. When caregivers start to neglect these activities from their lives, they tend to end up living resentfully, joylessly and with drained/depleted lives. When they take time to enjoy themselves their energy levels recharge. Practising what they enjoy doing will allow and caregivers to experience the effects of a deeper loving and caring relationship with those they try to help.

**Processing your own pain**: caregivers often sit next to pools of (their own) tears as wounded healers. The pool of tears may vary from person to person but we all have a pool of our own. If caregivers bring comfort and consolation only to others in pain without paying attention to their own, they are running the risk of compassion fatigue. If caregivers could find a human wailing wall where they can articulate their pain their capacity to live and love more deeply will be renewed. While the loving presence of God is experienced when caring and counselling those who listen to them, they will also find that processing their own pain enables them to reach out better into the hearts of others who experience pain. Caregivers

therefore should find a friend or colleague in whom they can confide and process their pain.

Try to curb tendencies towards compulsive caring: It is common for caregivers to become compulsive especially when Christ-followers feel they must get involved and must help every person in need. Hudson (1999) explains that people start to care compulsively when they ignore that tiny gap between feeling a person's pain and doing something for the suffering person. Caregivers sometimes rush into a caregiving situation without pausing first to discern how best to express the compassion they want to offer.

It might be that the need the person is experiencing is beyond our scope of practice, or that we neglect the role of the Holy Spirit try to fulfil all those roles, probably without success. Caregivers will experience compassion satisfaction if they honour the gap between feeling care and compassion for someone, and helping immediately. We need to acknowledge that we do not always know exactly what a person may need.

Compassion satisfaction may be experienced when caregivers set limits to their caring. You do not have to respond to every request that comes along (compare Anderson's explanation of bearing the right burden).

Caregivers will care less compulsively when they allow others to care for them. This may not be easy but allowing others to share the same care towards you will make you feel valued and loved.

**Develop a more celebrative lifestyle:** According to Hudson (1999:97) joy can be considered as the primary antidote given to us by God for the prevention of compassion fatigue. He argues that joy does not happen automatically although it is a gift from God but that it is also a duty. We need to make a choice to be happy or joyful.

Due to the work of Christ who overcame the powers of darkness and death, there is nothing that can separate us from the God's loving presence. On his ground we have to choose joy. This is however not so easy since most caregivers, especially if they have suffered greatly, could find this choice the greatest challenge of their faith. He continues to explain that when we open our lives to God's gift of joy we will start to develop a celebrative lifestyle.

Caregivers are sometimes faced with the pain and suffering of others to an extent where they become paralysed and blind to the things they can still celebrate. Practical examples are given to nurture a celebrative lifestyle: for instance, turning mealtimes into daily celebrations where

everyone can share in conversations and laughter together; family birthdays, fun times, giving thanks, or even just wearing clothes you like and enjoying the goodness of God.

Caregivers should learn how to celebrate since celebration is not just a spontaneous event, it is a choice.

This corresponds to the shifting of our positions and the notion of that in life we cannot always control what happens to us but how we can control our response to it. It is therefore possible for caregivers to experience compassion satisfaction when they take care of themselves in a way that ensures a healthy appetite for nourishing love and healing grace.

One can then say that it is of utmost importance that the training of caregivers in the healing professions should include self-care and the aspects that were raised and discussed in this chapter. Opportunities for caregivers to retreat to a dedicated venue and regain what they have lost will address the issues of prevention and-alert them to the warning signs of burnout, compassion fatigue and getting help.

The various coping skills should also be taught and caregivers should go on regular retreats to reflect on their own lives but also the lives of the people they care for and their relationship with God.

### 5.7 CONCLUSION

In <u>chapter 2</u> the impact of the HIV and AIDS pandemic was revisited. The enormity of the task that challenges caregivers and the extent of the burdens that they have to bear on a daily basis, and how it influences them in the execution of their caregiving tasks were indicated. Although it is difficult for someone not directly involved to comprehend the dynamics of caregiving, some idea was conveyed. The knowledge of who are involved in caregiving and the various levels of caregiving were sketched in order to get present a better understanding of the challenges to caregivers without the necessary support systems. These are circumstances that can lead either to utter despair and frustration or attitudes of coping with what is available.

In <u>chapter 3</u> some of the research objectives were to determine the nature of compassion fatigue and burnout, and whether they are fundamentally stress related or related to the over-exposure of human suffering. Compassion fatigue was explored as a side effect of caring and

concepts associated with compassion fatigue, such as burnout and vicarious traumatization were brought to bear on compassion fatigue. These phenomena and their negative influences on caregivers were explored and the cost of compassionate caregiving was outlined.

The signs and symptoms of compassion fatigue, burnout, and vicarious traumatization were highlighted and it became clear that a variety of negative experiences develop amongst people who care for others in very negative or traumatic experiences.

Burnout is seen by some researchers as a condition that occurs due the continuous adjustments that takes place in the work environment. Others see compassion fatigue as a form of burnout; but what became clear was that these two conditions differ in terms of nature and intensity. Burnout can occur without any personal contact or provider-recipient interaction. It is possible for caregivers to suffer from burnout (due to personal occupational goals and available resources) and compassion fatigue (due to the overwhelming exposure to other people's trauma and suffering).

When comparing burnout and compassion fatigue the researcher discovered that factors like work-related and organisational characteristics may contribute to burnout. Job-related stressors like client related stressors (i.e. increased patient perception and complexity); increased patient-to-caregiver ratios; social support factors (the level of education, collaborative practice provided and leader/peer support) also increase burnout. Even the degree of autonomy the ability to retain control over decision making in caregiving can contributes to burnout. Burnout in short refers to exhaustion in terms of professional identity and a feeling of overwhelmed incompetence.

Various points of view in the same vein contend that burnout results from the competitive nature of work environments and the ever-changing challenges people face, and not necessarily due to patient/client and caregiver relationship. The relationship was regarded as a contributing factor to emotional exhaustion, thought to be the root cause for burnout. As research has shifted from descriptive to inferential study designs, findings have strongly suggested that this caring relationship was not the key driver contributing to burnout.

Compassion fatigue is therefore not the same as burnout (although it is very difficult to distinguish between the two), although certain signs and symptoms may overlap and are related to stress from helping or wanting to help a traumatised person. Compassion fatigue

results actually from over-exposure to other people's traumatic events. Therefore we must take into consideration that caring for the traumatised or suffering patient does affect the caregiver and can cause harm in terms of attitude and ability. Compassion fatigue it is more likely to be the result of excessive over-identification or of over-investment.

<u>Chapter 4</u> considered the questions with which caregivers may be plagued when they experience the over-whelming effect of caring for those who suffer and are dying. God's involvement in human suffering was contemplated, as also how the theology of the cross opens up a new understanding of God's passion and compassion. Incomprehensible as it may appear, it stands out that suffering becomes a characteristic and feature of God's faithfulness to His promises and the theology of the cross reframes our understanding of God /our God images.

In the cross, God's weakness is a sign of His power and God becomes the wounded healer. This fact is important for pastoral care to the suffering, because it also displays the important theme of God's loving and solidarity with sufferers. A connection between the theology of the cross and compassion exists in the notion of God's compassion for suffering people and that God suffers for/because of people; God suffers with the suffering people; and God suffers for people. It is in this suffering that God reveals His compassion a notion of which caregivers should take cognizance and which would motivate caregivers to know that God is with them.

As was shown, caregivers in the thick of compassion fatigue may despair in the apparent hopelessness of their situation, even to the point of thinking that God is helpless to do anything about it. The opposite, abundant with hope amidst grim circumstances, may be referred to as a theology of compassion. Such a theology would imply indicators, elements, dimensions in which God is abundant.

God is compassion and the certainty that God is not absent can God in His omnipresence, omniscience and everlasting love ever be absent is the one factor that goes on to make sense despite all the incomprehensible circumstances, even your own that surround you.

<u>In chapter 5</u> the focus was on pastoral care to the depleted caregiver and how pastoral care may assist those who suffer from compassion fatigue. The retreat was discussed as a ministry model through which caregivers may benefit. Compassion fatigue was in the focus,

to how these threats weaken and cast a shadow on the human soul. It transpired that a person's life does not become meaningful when they are told what the meaning of life is supposed to be, but when they start to do meaningful things. Sometimes there is no meaning in suffering and the only meaning is that which people assign to their suffering.

A better understanding was sought of how people react when facing a crisis, the positions and attitudes they assume and how a shift in these position may help them to experience soulfulness and wholeness. When people shift their position regarding the meaningful acceptance of suffering when a reframing of their paradigm and even of their theology were afforded a time, a place and a space to happen it can mean that both patients and depleted caregivers will no longer ask *why* and *wherefore*. Out of God's faithfulness they discover the *whereto* and *to what purpose*.

"Where to" means that believers receive an answer: they discover God's faithfulness. It can be concluded that suffering is not God's will, but what happens to us while we suffer is what happens within us and through us.

Therefore, with reference to the research question, it emerged that caregivers do face various challenges while caring for others. Compassion fatigue may cause them to doubt their own abilities and calling, but pastoral care as a form of intervention may assist them to experience lower levels of compassion fatigue and higher levels of compassion satisfaction. As a spiritual virtue in the healing profession compassion makes up the core element of caring. Caregivers should get all the support necessary to deal with the challenges they face daily, working with death and suffering and needing to read the signs when they are running the risk of burnout or compassion fatigue and also where to recharge.

Pastoral care as a method of intervention can positively assist caregivers who suffer from compassion fatigue to shift their position despite the challenges they face, and open up new opportunities for growth.

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Apendixes A

# Compassion Satisfaction/Fatigue Self-Test for Helpers <sup>6</sup>

Helping others puts you in direct contact with other people's lives. As you probably have experienced, your compassion for those you help has both positive and negative aspects. This self-test helps you estimate your compassion status: How much at risk you are of burnout and compassion fatigue and also the degree of satisfaction with your helping others. Consider each of the following characteristics about you and your current situation. Write in the number that honestly reflects how frequently you experienced these characteristics in the last week. Then follow the scoring directions at the end of the self- test

Items About You
1. I am happy.
2. I find my life satisfying.
3. I have beliefs that sustain me.
4. I feel estranged from others.
5. I find that I learn new things from those I care for.
6. I force myself to avoid certain thoughts or feelings that remind me of a frightening experience.
7. I find myself avoiding certain activities or situations because they remind me of a fr ightening experience.
8. I have gaps in my memory about frightening events.
9. I feel connected to others.
10. I feel calm.
11. I believe that I have a good balance between my work and my free time.
12. I have difficulty falling or staying asleep.
13. I have outburst of anger or irritability with little provocation
14. I am the person I always wanted to be.
15. I startle easily.
16. While working with a victim. I thought about violence against the perpetrator.
17. I am a sensitive person.
18. I have flashbacks connected to those I help.
19. I have good peer support when I need to work through a highly stressful experience.
20. I have had first-hand experience with traumatic events in my adult life.
21. I have had first-hand experience with traumatic events in my childhood.
22. I think that I need to "work through" a traumatic experience in my life.
23. I think that I need more close friends.
24. I think that there is no one to talk with about highly stressful experiences.
25. I have concluded that I work too hard for my own good.
26. Working with those I help brings me a great deal of satisfaction.
27. I feel invigorated after working with those I help.
28. I am frightened of things a person I helped has said or done to me.
29. I experience troubling dreams similar to those I help.
30. I have happy thoughts about those I help and how I could help them.
 31. I have experienced intrusive thoughts of times with especially difficult people I helped.

O=Never l=Rarely 2=A Few Times 3=Somewhat Often 4=Often 5=Very Often  33. I am pre-occupied with more than one person I help.  34. I am losing sleep over a person I help's traumatic experiences.  35. I have joyful feelings about how I can help the victims I work with.  36. I think that I might have been "infected" by the traumatic stress of those I help.  37. I think that I might be positively "inoculated" by the traumatic stress of those I help.  38. I remind myself to be less concerned about the wellbeing of those I help.  39. I have felt trapped by my work as a helper.  40. I have a sense of hopelessness associated with working with those I help.  41. I have felt "on edge" about various things and I at tribute this to working with certain people I help.  42. I wish that I could avoid working with some people I help.  43. Some people I help are particularly enjoyable to work with.  44. I have been in danger working with people I help.  45. I feel that some people I help dislike me personally.  Items About Being a Helper and Your Helping Environment  46. I like my work as a helper.  47. I feel like I have the tools and resources that I need to do my, work as a helper.  48. I have felt weak, tired, run down as a result of my work as helper.  50. I have flott depressed as a result of my work as a helper.  51. I am unsuccessful at separating helping from personal life.  52. I enjoy my co-workers.  53. I depend on my co-workers to help me when I need it.  54. My co-workers can depend on me for help when they need it.  55. I trust my co-workers.  56. I feel little compassion toward most of my co-workers  57. I am pleased with how I am able to keep up with helping technology.  58. I feel I am working more for the money/prestige than for personal fulfillment.  59. Although I have to do paperwork that I don't like, I still have time to work with those I help.  60. I find it difficult separating my personal life from my helper life.  61. I am pleased with how I am able to keep up with helping technology.  62. I have a	32.	I have suddenly and involuntarily recalled a frightening experience while working with a person I helped.						
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	63.	I have thoughts that I am a "failure" as a helper.						
65. I have to deal with bureaucratic, unimportant tasks in my work as a helper.	64.	I have thoughts that I am not succeeding at achieving my life goals.						
	65.	I have to deal with bureaucratic, unimportant tasks in my work as a helper.						
	66.	I plan to be a helper for a long time.						

#### **Self-Test Scoring Instructions**

Please note that research is ongoing on this scale and the following scores should be used as a guide, not confirmatory information.

- 1. Be certain you respond to all items.
- 2. Mark the items for scoring:
  - a. Put an *x* by the following 26 items: 1-3, 5, 9-11, 14, 19, 26-27, 30, 35, 37, 43, 46-47, 50, 52-55, 57, 59, 61, 66.
  - b. Put a check by the following 16 items: 17, 23-25, 41, 42, 45, 48, 49, 51, 56, 58, 60, 62-65.
  - c. Circle the following 23 items: 4, 6-8, 12, 13, 15, 16, 18, 20-22, 28, 29, 31-34, 36, 38-40, and <math>44
- 3. Add the numbers you wrote next to the items for each set of items and note:

Your potential for Compassion Satisfaction (x)

118 and above = extremely high potential

100-117 = high potential

82-99 = good potential

64-81 = modest potential

below 63 = low potential

Your risk for Burnout (check)

36 or less = extremely low risk

37-50 = moderate risk

51-75 = high risk

76-85 = extremely high risk

Your risk for Compassion Fatigue (circle)

26 or less = extremely low risk

27-30 = low risk

31-35 = moderate risk

36-40 = high risk

41 or more= extremely high risk

Chart by circling the appropriate score categories below for your assessed level of risk.

Level of Risk	Burnout Level	Compassion Fatigue (CF) Level	Satisfaction Level
High/Extremely High	51 or more	36 or more	82 or more
Moderate	37- 50	31 - 35	64- 81
Extremely Low/Low	36 or less	30 or less	63 or less

### **APPENDIX B**

Self-Care in Life Inventory <sup>2</sup>				
Basic Self-Care Needs	Yes	No	Goal	
1. Do I usually get enough sleep?				
2. Do I usually eat something fresh			'	
and unprocessed every day?				
3. Do I allow time in my week to				
touch nature, no matter how				
briefly?				
4. Do I get enough sunlight, especially				
in wintertime?				
5. Do I see my medical practitioner at				
least once a year?				
6. Do I see a dentist every six months?				
7. Do I get regular sexual thrills?				
8. Do I get enough <i>fun</i> exercise?				
9. Am I hugged and touched amply?				
10. Do I make time for friendship?				
11. Do I nurture my friendships?				
12. Do I have friends I can call when I				
am down, friends who really listen?				
13. Can I honestly ask for help when I				
need it?				
14. Do I regularly release negative				
emotions in a healthy				
15. Do I forgive myself when I make a				
mistake?				
16. Do I do things that give me a sense				
of fulfilment, joy and purpose?				
17. Is there abundant beauty in my life?				
18. Do I allow myself to see beauty and				
to bring beauty into home and				
office?				
19. Do I make time for solitude?				

20. Am I getting daily or weekly	
spiritual nourishment?	
21. Can I remember the last time I laughed until I cried?	
22. Do I accept myself for who I am?	
Total of Yes and No responses <sup>3</sup>	

Self Care at Work Inventory <sup>4</sup>			
Self-Care @ Work <sup>5</sup>	Yes	No	Comments/Reflections
Do I take a lunch break every day and do something unrelated to work?			•
2. Do I work reasonable hours?			
3. Do I schedule "breathing room every day so I can step back, and re-evaluate my priorities .			
4. Is my office free of clutter?			
5. Do I have adequate lighting and clean air?			
6. Do I delegate work to free my time and empower others?			
7. Do my family/ friends honour my work time? If no, have I asked them?			
8. Do I have blocks of uninterrupted time without distractions and interruptions?			
9. Do I have a DO NOT DISTURB Sign ?			
10. Have I scheduled specific times for returning phone calls and checking email?			
11. Have I stopped taking on more than I can handle?			
12. Do I drink enough water when I am at work?			
13. Do I have comfortable shoes/slippers at my office?			

14. Do I schedule time off from work (sick leave and/or vacation time) to take care of myself?		
15. Do I have someone to talk with about my professional life?		-
16. Do I have creature comforts that make my office pleasant? (music and other sounds, aroma, artwork)		
17. Do I say yes to commitments that I later regret?	8	

**Yes** number lower than 10 indicates violation of standards of self-care and highly vulnerable to health and mental health problems

More than 8 no answers is a violation of the Standards of Self Care

Adapted from Life Makeovers (2000) by Cheryl Richardson © Green.