

Towards the development of a coping model for the well-being of patients with transverse myelitis

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Dedication

This study is dedicated to my daughter, Alet Uys.



Thank you, Alet, for being a brave person.

Thank you for your love.

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I wish to express my sincere appreciation to:

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Summary

Transverse myelitis (TM) is a rare auto-immune inflammatory disease in which the patient's immune system attacks their spinal cord resulting in an unpredictable degree of neurologic disability, ranging from complete recovery to quadriplegia. TM patients often experience insufficient assistance towards understanding causes of the illness and have little to depend on in trying to deal with it. This study explores psychological strengths and coping strategies used by TM patients in coping with the illness.

A theoretical framework of positive psychology with a strong focus on seven constructs, namely positive coping, searching for meaning, benefit finding, hope, sense of humour, resilience, as well as religion and spirituality is presented. The main data collection strategy for this study was the gathering of stories as a form of conversation. These were subjected to thematic analysis by interpretative phenomenological analysis (IPA) focused on identifiable themes and patterns of living and behaviour.

The emerging patterns and identified fortigenic qualities were then considered, analysed and argued in relation to corresponding coping strategies. A model for the psychological coping and well-being of TM patients, based on emphasising the positive and constructive and considering existing models and strategies for the well-being of patients, was developed. The strategic and therapeutic model is presented in easily understandable language for the benefit of any care-giver (e.g. family member, friend or nurse) or the patient him/herself.

Keywords: transverse myelitis (TM), neurological disease, spinal cord, myelin, autoimmune disease, demyelating, psychological strategy, positive psychology, psychology construct, narrative, thematic analysis, interpretative phenomenological analysis (IPA), fortigenic quality, coping strategies, coping model, searching for meaning, benefit finding, hope, sense of humour, resilience, religion, spirituality.

Opsomming

Transvers miëlitis is 'n seldsame, outo-immuun, inflammatoriese, demieliniserende siekte van die rugmurg, wat ernstige neurologiese ontwrigting en ernstige, onvoorspelbare en dikwels aftakelende pyn veroorsaak. TM pasiënte ontvang onvoldoende hulp met die verstaan van die onderliggende oorsake van die siekte en het ook min om op staat te maak ten einde verligting te kry en om die siekte te hanteer. Hierdie studie stel vas wat die sielkundige sterkte en die hanteringsmeganismes van TM pasiënte is.

'n Teoretiese raamwerk van positiewe sielkunde met 'n sterk fokus op sewe konstrukte, naamlik positiewe hanteringsmeganismes, soeke na betekenis, baatvinding, hoop, sin vir humor, sielkundige veerkragtigheid, asook godsdiens en spiritualiteit, word aangebied. Die hoof data-insamelingsmetode was die versameling van stories as 'n weergawe van gesprek.

Die patrone en fortigeniese kwaliteite wat deur die TM pasiënte se stories na vore gekom het, is met betrekking tot ooreenstemmende hanteringstrategieë oorweeg, geanaliseer, beredeneer en geïnterpreteer. 'n Model vir die sielkundige hantering en welsyn van TM pasiënte is ontwikkel. Dié model is gebaseer op die positiewe hanteringsmeganismes van die TM pasiënte. Dit is ontwikkel in oorleg met bestaande modelle wat op die welsyn van pasiënte fokus en aangebied in taal wat vir pasiënte en helpers toeganklik sal wees.

Sleutelwoorde: transvers miëlitis (TM), miëlien, neurologiese siekte, rugmurg, neurologies ontwrigtend, outonome disfunksie, inflammatoriese outo-immuun siekte, demieliniserend, positiewe sielkunde, tematiese ontleding, interpretatiewe fenomenologiese ontleding, fortigeniese eienskap, hanteringstrategieë, hanteringsmodel, positiewe hanteringsmeganismes, soeke na betekenis, baatvinding, hoop, humorsin, sielkundige veerkragtigheid, godsdiens, spiritualiteit.

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Chapter 1

Introduction: in search of answers

1.1 Introduction

A very ill woman, in pain, once said: "I am willing to go on with life, but before I can go on, I need to know what this battle is about." This mirrors the complex emotions of many people struggling with serious illness. They seek reasons for their illness, contemplate discussions with medical practitioners and specialists and try to understand the illness and ~~the~~ battle from religious or psychological perspectives. The neurological disease, *transverse myelitis* (TM) is an illness that often leaves the patient relatively helpless in finding options to deal with it. Because TM disrupts and consequently confuses the neurological system, it is an illness that causes severe and unpredictable pain. It can debilitate the person completely. Despite medical assistance, people suffering from TM generally experience insufficient assistance towards understanding causes of the illness and have little to depend on in trying to get relief from the illness or in dealing with it.

This study aims to explore psychological strategies for patients with TM in coping with the illness.

1.2 Research problem

TM is a relatively unknown disease. Only one in a million people worldwide suffer from TM (Krishnan, Kaplin, Deshpande, Pardo & Kerr, 2004). It is a complex neurological disease that patients have difficulty to understand.

Transverse myelitis (TM) is the neurological disorder caused by inflammation across one segment of the spinal cord. It is a disabling disease of the central nervous system (Jeffrey, Mandler & Davis, 1993; Parker & Parker, 2002). According to Martz and Livneh (2007) people with chronic illnesses and disabilities face enormous challenges even if they have access to emotional, physical and social support. People living with such illnesses and disabilities frequently perceive their daily living as uncontrollable and unpredictable.

Feelings of inwardly-directed revulsion are often experienced by people with chronic conditions, especially in communities where physical beauty, strength and perfection are emphasised (Martz & Livneh, 2007). Resentment of altered physical functioning and appearance seem to stem from the desire to lead %normal+ and %perfect+ lives. For most people with chronic illnesses and disabilities, the onset of such an illness is a time of psychological distress.

With regard to the psychological care TM is, in many ways, a neglected disease. There has been no prior academic attempt to systematically explore the coping strategies of TM patients and this research attempts to develop a possible coping model for the well-being of these patients. Because of the intensity of the disease there may be TM patients in need of psychological interventions. This research focuses on the coping of TM patients which could contribute to the development of psychological interventions. Existing research with patients with other chronic illnesses will be used as a research context.

As a point of departure towards establishing the interventions, it is observed that the approach of positive psychology with its emphasis on fortigenic qualities

(Snyder & Lopez, 2005) provides a way to investigate coping lifestyles. By utilising this approach the strengths experienced TM patients may have towards coping with extreme challenges can be identified and explored. Fortigenic qualities include coping strategies and psychological resources. Established personal coping strategies of experienced TM patients need to be identified and integrated with alternative coping strategies to assist those in need of psychological assistance. Coping strategies aimed at dealing with or alleviating physical and emotional pain will receive special attention. The coping strategies used by experienced TM patients may contribute to the development of a coping model to assist TM patients in need of psychological assistance.

In a bid to harness available fortigenic capabilities, identification and exploration are required regarding such strengths prevalent in experienced TM patients. Fortigenic capabilities will also include coping strategies and psychological resources. Established personal coping strategies of patients need to be identified and integrated with alternative coping strategies to assist sufferers in living with TM. Coping strategies aimed at dealing with or alleviating physical and emotional pain will receive special attention. The coping strategies used by experienced TM patients may contribute to the development of a coping intervention model to assist TM patients in need of psychological assistance.

1.3 Interest in the field of research: personal challenge

The background and experiences of the author hold the key to the understanding of the motivation towards conducting and refining this research. It will also highlight the impetus for using the approach proposed above.

In 2000, when my daughter was eleven years old, she became sick and was diagnosed with TM. Her symptoms over several months included sensory disturbance, limb weakness, bladder dysfunction and severe lower back pain. It was a traumatic time and experience for the family. The period between the

onset of the illness and any recovery cannot be predetermined. As discussed in chapter 2, recovery may be absent, partial or complete. If no improvement occurs within three months, significant recovery is unlikely.

Berman, Feldman and Alter (1981) state that one third of TM patients recover completely from TM. Another third recovers partly, leaving them with certain problems such as spastic gait, sensory dysfunction and prominent urinary urgency and incontinence. The remaining one-third suffers permanent impairments that affect their ability to perform ordinary tasks of daily living. We are therefore humbled by the fact that my daughter recovered fully and developed into a currently young healthy university student. (See Annexure A for an essay by Alet Uys regarding her experience with TM.)

Since the onset of my daughter's illness I have become intrigued by the occurrence, symptoms and treatment of TM. Because this disease has debilitating effects on patients, it seems that the physical and medical sides of TM are the main foci of research. I discovered that very little literature is available with regard to the psychological impact that TM has on patients. My daughter's illness and recovery led me to become more involved with those who suffer from TM. In 2003 I became the joint support group leader of the South African TM group. In this position I have had the opportunity of lengthy discussions with TM patients, conducted interviews with neurologists and became stimulated through relevant literature and academic papers on this disease. I have wanted to help the patients deal with the illness but could not find relevant literature on coping with the illness.

1.4 Interest in the field of research: Theoretical challenge

During the same time, I became interested in the approach of positive psychology. Exploring topics such as optimal development, hope and resilience, sense of humour, spirituality and religion became part of my daily routine. The

work of Strümpfer (1990, 1995, 2004, 2005) especially intrigued me as I found his treatises particularly helpful in understanding people's strengths, resources and resilience (Snyder & Lopez, 2005; Strümpfer, 1995; Wissing & Van Eeden, 2002). Fortigenesis seemed to form an enticing bulwark for constructing bridges towards support for TM patients and towards alleviating their suffering. This thesis presents construction work on such a bridge.

1.5 Objectives of the research

The objectives of this study are to:

- Explore the coping strategies of patients with transverse myelitis,
- determine which coping strategies are most likely to successfully assist sufferers in their daily dealing with TM and
- develop, based on the analysis, a coping model for the well-being of patients with transverse myelitis.

1.6 Motivation for the study

The research pertains to the psychological well-being of TM patients and their care-givers. An insight into coping strategies and resources could be of value for physicians as well as for psychologists and families when dealing with TM patients. The researcher is aware of the fact that a primary coping model is likely to present its own limitations and may not be the final answer to the alleviation of the debilitating effects of TM. It may, however, pave the way to reduce suffering by offering patients some control over their symptoms and emotions through hitherto relatively unknown psychological techniques. The findings may serve as guidelines for TM patients that have recently been diagnosed. It may supply them with valuable information regarding principles that need to be considered to cope with TM.

1.7 Research design

A qualitative research approach, using an interpretative phenomenological analysis (IPA), is used as a research design. According to Ratcliff (2006) qualitative research has many qualities and can be conducted from various theoretical perspectives.

Qualitative research is descriptive and interpretive in nature, is done in a naturalistic context and can be done from a phenomenological point of view. Hoepfl (1994) posits that there are several considerations when deciding to adopt a qualitative research methodology. Her claim is that qualitative methods help researchers to understand any phenomenon of which little is known about. Hydén (1997) states that:

One of our most powerful instruments for expressing suffering and experiences related to suffering, is the narrative. Patients' narratives give voice to suffering in a way that lies outside the domain of the biomedical voice. This is probably one of the main reasons for the emerging interest in narratives among social scientists engaged in research on biomedicine, illness and suffering+(p. 49).

In chapter 4 the research focus is discussed in detail.

1.8 Data collection

Narratives and stories, verbal or by e-mail, were used as methods of interaction between the participants and the researcher. These methods accelerated the process whereby the researcher could achieve understanding of participants' perspectives on their daily lived experience (Patton, 2002). Five patients were identified through the TM support group as being accessible, eligible, willing and able to participate in this research. These patients were contacted

telephonically. The aim of the research was briefly presented and it was stated that the bulk of information sharing would be conducted via e-mail. This would be done through the communication channels of the TM support group.

Bury (1982) posits that chronic illness can be seen as a disturbance of one's continuing life. Chronic illness changes the relationship between the patient's body, the self and his or her surrounding world. For the chronically ill, it is therefore of central importance to reconstruct his or her own life story (Williams, 1984). When a chronically ill person tells his or her story within the framework of his or her own life history, it becomes possible to give meaning to events that have disrupted and altered the course of that person's life (Hydén, 1997). The topic of suffering deserves attention in the TM context as well. Kleinman (1988) claimed that with regard to suffering, the narrative is the form in which patients give voice and shape to their lives (Hydén, 1997).

The initial telephone calls were followed up by e-mail communication. To obtain data TM patients were asked to write the narratives of their lives and to e-mail it back to the researcher. This method of data collection was attractive because the number of people suffering from TM in South Africa is small and they are spread widely over the vast country. The cost of face to face interaction, in terms of time and finances, would have been prohibitive to the researcher, even though the number of available participants was small. Electronic correspondence was furthermore chosen in a bid to collect the data with minimal disturbance to the participants and not to aggravate their suffering. Lengthy telephone conversations would probably have been inconvenient and tiresome for the participants because of pain and associated conditions.

Children with TM in South Africa were excluded from the research as the study concentrated on adults only. After obtaining biographical information, participants were requested to present their perceptions of their world and of the important events in their lives. The idea was to help them construct a story of their lives. Detail of the instructions is given in chapter 4.

1.9 Data analysis

According to Aronson (1994) ideas from conversations with participants, merge. These ideas can be understood by creating a thematic analysis, in this case from an interpretative phenomenological analysis (IPA) perspective. The IPA focuses on identifiable themes and patterns of living and/or behaviour (see chapter 5). Stories as a form of conversation were collected by e-mail and analysed in various steps to identify patterns of experiences.

Each pattern of experiences is fleshed out with related data from all participants. Themes are defined as units derived from patterns such as conversation topics, vocabulary, recurring activities, meanings and feelings. Themes are therefore identified by bringing together components or fragments of ideas or experiences, which are often meaningless when viewed in isolation. Themes that emerge from the participants' stories are pieced together to form a comprehensive picture of collective experiences. It is the challenge and responsibility of the analyst to establish the coherence of ideas and it is therefore important to study the themes in a meaningful way (Rapmund & Moore, 2000).

The next step in the process of thematic analysis is to build a valid argument for choosing the themes. A developed theme-line helps the researcher to develop, oversee, control and motivate the process. It is essential to find depth and detail in the data and represent the participants' view and situation as fairly as possible (Charmaz, 2000, p.10).

The emerging patterns and how they correspond with the fortigenic qualities are considered, analysed and argued. This was the process selected and used for the data analysis of this study.

1.10 Developing a coping model

From the patterns, as determined from the stories and the corresponding coping strategies, a model for the psychological coping and well-being of TM patients was developed. The principle of this model was to emphasise the positive and the constructive, i.e. to develop ways of dealing with the debilitating symptoms of TM. Existing models for the well-being of patients as described in the literature (Lazarus & Folkman, 1984; Mills, 1995) were studied. Further exploration of later models (Larsen & Hummel, 2009) was used to determine model principles as well as to determine strategic and possible therapeutic arrangements to the benefit of patients.

1.11 Overview of chapters

The research is reported in the form of various chapters. Chapter 1 gives an introduction to the research topic and explains the researcher's interest in the field of the research. The objectives of the research, the research design and methods are introduced as well.

Chapter 2 places the research question in the context of TM patients. An in-depth, yet brief, discussion on TM follows. The discussion on TM includes a theoretical medical framework presenting symptoms, prognosis and occurrence. The relevance of pain to TM patients and existing models for the well-being of patients of serious illnesses are investigated.

In chapter 3 the background, the historical development and a theoretical framework of positive psychology are discussed. The focus is on seven psychology constructs relevant to this research, namely positive coping, searching for meaning, benefit finding, hope, sense of humour, resilience, as well as religion and spirituality.

In chapter 4 the research methodology of the study is discussed. Procedures and steps followed to collect research narratives are described and motivated. The ontology and epistemology of the IPA framework and qualitative research design are explained and reviewed. The research questions and aims, the selection of participants, data collection and analyses are discussed. Ethical considerations of the research process and intervention plans are highlighted.

In chapter 5 the results of the analyses of the research narratives are discussed. A synergy and synthesis of the narratives, reflections and research material are included.

In chapter 6 a proposal for a model for the well-being of TM patients is presented based upon the findings of the study. It is indicated how material can be developed to be used in empowering TM patients to benefit from this study

Chapter 7 concludes with critical comments, recommendations for future research and a discussion on the values of the research findings.

1.12 Chapter conclusion

The purpose of the study is to attend to the suffering of TM patients and the debilitating effects of the illness. The study aims to understand how patients cope psychologically with the debilitating effects of the illness. This is done to assist TM patients in coping in their daily lives and to assist professionals in advising TM patients accordingly. Pain inhibits a patient on various levels: physical, psychological, economical, social and professional. If TM patients can be assisted to deal with their painful handicap, their well-being may be enhanced.

Chapter 2

Transverse myelitis, pain and coping models for chronic illness and disability

2.1 On transverse myelitis: an overview

2.1.1 Introduction

An understanding of TM, the symptoms as well as TM patients' experiences create the contextual backdrop against which the study takes place. In this chapter the nature of transverse myelitis (TM) and the role of pain in TM will be discussed. The chapter starts with an overview of TM, including the symptoms, the causes, how a diagnosis is made, what the possible treatments are, the occurrence of TM and, finally, what the prognosis is. Medical terminology used in this discussion is presented in a medical glossary in Annexure B.

After an extensive discussion on TM, the relevance of pain in TM, definitions of pain, pain management, a psychosocial approach to pain, the genetic role of pain, as well as coping choices for chronic illness will be elaborated on.

2.1.2 What is transverse myelitis (TM)?

According to Parker and Parker (2002) as well as Jeffrey, Mandler and Davis (1993) transverse myelitis (TM) is a neurological disorder caused by inflammation across one segment of the spinal cord. It is a disabling disease of the central nervous system (CNS). TM is a very uncommon disease.

As the term *transverse* suggests, the inflammation presents across the width of the spinal cord. Attacks of inflammation can damage or destroy myelin, the fatty insulating substance that covers nerve cell fibres. Parker and Parker (2002) state that the damage causes interrupted communications between the nerves in the spinal cord and the rest of the body, leading to varying degrees of paralysis.

TM is described as a clinical syndrome in which a deranged autoimmune-mediated process takes place. It is a potentially devastating focal inflammatory disorder of the spinal cord (Krishnan, Kaplin, Deshpande, Pardo & Kerr, 2004, p. 236). This process causes neural injury to the spinal cord, resulting in sensory alterations, autonomic dysfunction and varying degrees of weakness. These authors explain that TM can exist as part of a multi-focal central nervous system disease like multiple sclerosis, a multisystemic disease like systemic lupus erythematosus, or as an isolated, idiopathic disease. Examples of other autoimmune diseases which are more common than TM include rheumatoid arthritis (in which the immune system attacks the joints) and multiple sclerosis, (in which myelin is the target of autoimmune attack and demyelination, which may cause paralysis, takes place).

Myelin is the white matter coating our nerves that enables the nerves to conduct messages between the brain and other parts of the body efficiently and rapidly by curtailing ion leakage to surrounding fluids and other semi-conductive tissue. It consists of a layer of proteins packed between two layers of lipids or fat. Myelin is produced by specialised cells, namely oligodendrocytes in the central nervous system and Schwann cells in the peripheral nervous system. Myelin sheaths wrap themselves around axons, the threadlike extensions of neurons that make up nerve fibres. Each oligodendrocyte can myelinate several axons (Valk & van der Knaap, 2005).

Myelin can further be explained as a collection of lipid fats and proteins that sheath the long extensions of nerve cells (neurons) called axons, as depicted in Figure 1 (from Squire, Berg & Bloom, 2008) below. Myelin increases the speed with which nerve signals (impulses) move down the axons considerably. A thin myelinated axon transmits impulses at anything from five to thirty metres per second whereas an unmyelinated axon transmits the impulses at about two metres per second. This indicates that, whereas a foot can receive fresh operational instructions and report position and sensation back to the brain, say, every 80 milliseconds through myelinated axons, this can only happen slower than once per second in the absence of the myelin.

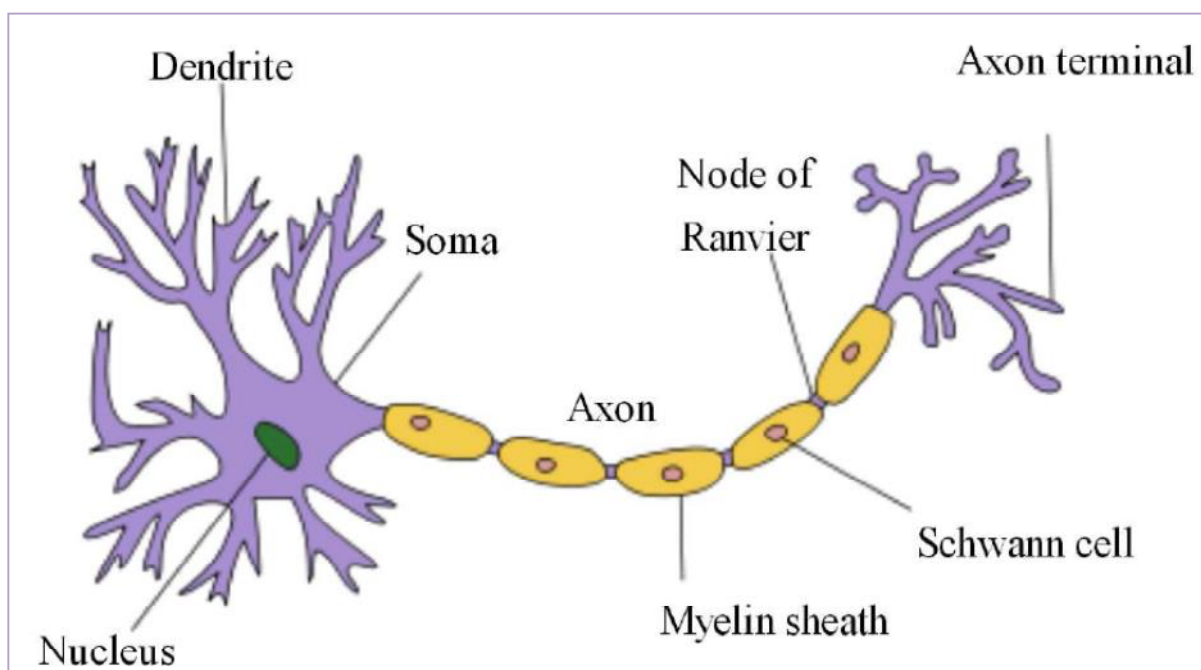


Figure 1: The soma (body) of a typical neuron

Valk and Van der Knaap (2005) describe demyelination as the loss of myelin from around the axon, for instance by progressive damage to the myelin structure. This leads to ineffective and delayed propagation of nerve impulses. TM lesions can be observed as a disturbance in magnetic resonance imaging (MRI) readouts and the disturbance represents inflammation during the attack. The lesion may represent scar tissue after the attack. As the disease progresses the axons themselves are ultimately destroyed.

Because there is compelling evidence that the destruction is caused by the body's own immune system, TM is classified as an autoimmune disease. Demyelination generally occurs at the thoracic level of the spinal cord. This causes serious problems with leg movement as well as with bowel and bladder control; which requires signals from the lower segments of the spinal cord to the lower limbs (Berman et al., 1981). Because the spinal cord is responsible for motor, sensory and autonomic nerves of the central nervous system, diseases such as TM can lead to paralysis (Martz & Livneh, 2007).

Psychologically a person may experience depression often only once he or she realises the impact of the central nervous system disease on his or her life (Martz & Livneh, 2007). Less serious depressive reactions, not unlike grieving, are also found in persons who are processing their diagnosis of a central nervous system disease (Martz & Livneh, 2007).

2.1.3 Occurrence

Globally TM is a rare disease with an incidence of between one and eight new patients per million people per year (Krishnan et al., 2004).

TM occurs in adults and children of both genders and in all races (Parker & Parker, 2002). No familial predisposition is apparent. The peak number of new cases per year appears to occur between the ages of ten and nineteen years as well as between thirty and thirty nine years. Krishnan et al. (2004) continue to explain that most TM patients have it as a monophasic disease, while up to twenty percent can have recurrent inflammatory episodes within the spinal cord. Because of its variety of symptoms, TM is often misdiagnosed. The author is a group leader of the South African TM support group. At the time of the research the group has thirty five registered members, including adult men and women as well as children.

2.1.4 Symptoms

According to Lynn (1997) and Parker and Parker (2002) TM symptoms develop over several hours to several weeks. The condition of forty five percent of TM patients worsens significantly within the first twenty four hours. The spinal cord carries motor nerve fibres to the limbs and trunk and sensory fibres from the body back to the brain. TM occurs when inflammation within the spinal cord interrupts these pathways and causes the characteristic symptoms (Krishnan et al., 2004).

TM, according to Krishnan et al. (2004), is characterised by a focal inflammation within the spinal cord. The inflamed area causes clinical manifestations of neural dysfunction of motor, sensory and autonomic pathways. There is often a clearly defined rostral border of sensory dysfunction and evidence of acute inflammation that can be seen clearly by performing a spinal MRI and lumbar puncture.

Berman et al. (1981) and Stone (1997) explain that because the lesions can form anywhere in the spinal cord, TM can produce a wide variety of symptoms.

The following symptoms of TM have been observed:

- Sensory disturbance (Berman et al., 1981; Krishnan et al., 2004; Lynn, 1997),
- limb weakness (Berman et al., 1981; Lynn, 1997),
- dysfunction in bladder control,
- bowel dysfunction,
- lower back pain (Lynn, 1997),
- radicular pain (pain *radiated* along a single spinal nerve),
- tingling feeling or numbness in legs,
- diminished sensations of temperature (Berman et al., 1981),
- tight and very painful banding or girdle-like sensation around the lower back (Berman et al., 1981; Krishnan et al., 2004),

- extreme sensitivity to touch around the lower back (Berman et al., 1981),
- incomplete evacuation or bowel constipation,
- increased urinary urgency,
- sexual dysfunction (Krishnan et al., 2004),
- depression (Kaplin, Krishnan, Deshpande, Pardo, Kerr, 2005).
- fatigue,
- spasticity,
- nerve pain,
- pain,
- depending upon the level of spinal cord lesion the arms of patients are affected in some cases(Berman et al., 1981),
- cases of an inability to breathe without assistance,
- 50% of patients lose all leg movement (Krishnan et al., 2004) and
- loss of spinal cord function (Parker & Parker, 2002).

2.1.5 Pathogenesis (causes) of TM

TM may occur in the setting of another illness or in isolation. When TM occurs without apparent underlying cause, it is referred to as idiopathic TM (Lynn, 1997). Idiopathic TM is a result of abnormal or inexplicable activation of the immune system against the spinal cord.

Possible illnesses and infections preceding TM may include:

- Viral infections: herpes simplex, herpes zoster, cytomegalovirus, Epstein-Barr virus, enteroviruses (poliomyelitis, Coxsackie virus, echovirus), human T-cell, leukaemia virus, human immunodeficiency virus, influenza, rabies.
- Bacterial infections: mycoplasma pneumoniae, lyme borreliosis, syphilis, tuberculosis.

- Postvaccinal: rabies, cowpox.
- Systemic autoimmune diseases like systemic lupus erythematosus, Sjögren's syndrome, sarcoidosis, multiple sclerosis, paraneoplastic syndrome.
- Vascular diseases like thrombosis of spinal arteries, vasculitis secondary to heroin abuse and spinal arteriovenous malformation. Vascular TM cannot be idiopathic TM because vascular TM is in actual fact a spinal stroke and it rules out idiopathic TM.

The definite cause of idiopathic transverse myelitis is unknown, but most evidence suspects a deranged autoimmune process to be an underlying cause. This means that the patient's own immune system is abnormally stimulated so that it attacks the spinal cord and causes inflammation and myelin damage.

Lynn (1997) explains that TM often develops in the setting of viral and bacterial infections (e.g. rubeola, varicella, variola, rubella, influenza and mumps). She states that about one third of the TM patients report a febrile illness (flu-like illness with fever) in close relationship to the onset of neurologic symptoms. In certain cases, there is a direct invasion and injury to the spinal cord by the infectious agent itself (especially poliomyelitis, herpes zoster and HIV/Aids). A bacterial abscess can also develop around the spinal cord and injure the cord through compression, bacterial invasion and inflammation.

However, in many cases infection causes a derangement of the immune system, which leads to an indirect autoimmune attack on the spinal cord, rather than a direct attack by the organism. A theory to explain this abnormal activation of the immune system towards human tissue is termed "molecular mimicry". This theory postulates that an infectious agent may share a molecule, which resembles or "mimics" a molecule in the spinal cord. When the body mounts an immune response to the invading virus or bacterium, it coincidentally targets the spinal cord molecule with which the invader shares structural characteristics. This leads to severe inflammation and injury within the spinal cord (Kaplin, Krishnan et al., 2005; Lynn, 1997).

Though the exact causes of TM remain unknown, recent advances have suggested that specific cytokine derangements are likely to contribute to sustained disability (Krishna et al., 2004). According to Sahni, Garg, Garg, Agarwal and Singh (2008), heroin overdose can also cause various rare neurological complications like transverse myelopathy, mononeuropathy, plexopathy, acute inflammatory demyelinating polyradiculoneuropathy, rhabdomyolysis, compartment syndrome, fibrosing myopathy and acute bacterial myopathy+(p. 153).

A medical factor that plays a role in the cause of TM, is elevated IL-6 levels. Kaplin, Deepa, Deshpande, Scott, Krishnan, Carmen and Kerr (2005) explain that IL-6 is a glycoprotein cytokine that mediates signal transduction between immune cells. IL-6 can be described as a protein that is secreted by the lymph system cells that affects the activity of other cells and is significant in controlling inflammatory responses. This protein has previously been implicated in mood and concentration disorders, as well as neural diseases such as transverse myelitis, MS, Parkinson disease, Alzheimer's disease, HIV, encephalopathy and cognitive impairment. The researchers have recorded that depression is a common symptom of TM (Kaplin, Deepa et al., 2005).

A noteworthy finding in this regard is that, with TM, there is no correlation between clinical depression and disability. More severe physical deficits in a TM patient did not necessarily mean the TM patient was more likely to be depressed. In fact Kaplin, Deepa et al. (2005) found a correlation between depression and the number and severity of attacks on the nervous system of TM patients, rather than a correlation between depression and the TM patients' physical deficits.

Kaplin, Deepa et al. (2005) found that depression in TM patients did not correlate with motor disability, bladder disability or sexual function. The variability in pain bore a slight correlation with depression; an increase in pain caused an increase in depression.

Kaplin, Deepa et al. (2005) noted that cytokines play an important role in the pathogenesis of TM. These researchers examined the diffusible derangements within the cerebrospinal fluid of a group of TM patients with a cytokine antibody array. They found that IL-6 levels are indeed dramatically elevated in the spinal fluid of TM patients.

2.1.6 Diagnosis

Neurologists diagnose TM by taking a medical history of the patient and performing a thorough neurological examination (Krishnan et al., 2004). According to Lynn (1997) the general medical history and physical examination are first performed but often do not give clues about the cause of spinal cord injury. A mass-occupying lesion, which might be compressing the spinal cord, should be ruled out by the doctor who evaluates a patient with complaints. Potential lesions, which might compress the cord, could include a tumour, herniated disc, stenosis (a narrowed canal for the cord) and an abscess. It is important to establish whether such lesions are present, because early surgery to remove the compression may sometimes reverse neurological injury to the spinal cord. The way to rule out such a compressive lesion is to do magnetic resonance imaging (MRI) of the appropriate levels of the spinal cord of the patient.

If an MRI is not available or the images are equivocal, myelography must be performed. Lynn (2004) continues to explain that a myelogram is a set of X-rays taken after a lumbar puncture has been performed either in the neck or lower back. A contrast agent (dye) is injected into the dural sac that surrounds the spinal cord. The patient is then tilted up and down (to let the dye flow and outline the spinal cord) while the X-rays are taken.

According to Lynn (2004), if no *mass* lesion is visible within or outside the spinal cord after an MRI or a myelogram, the patient most probably has transverse

myelitis. The MRI can sometimes show an *inflammatory* lesion within the cord. The cause of the inflammation is difficult to establish, because biopsy is seldom done on the spinal cord as it could cause damage.

The next step for the attending physician is to have general blood tests done and to check for systemic lupus erythematosus, Sjögren's syndrome, HIV infection, vitamin B12 levels (to rule out deficiency) and to have a test done for syphilis. Subsequently a lumbar puncture is performed to obtain fluid for studies, including a white cell count, protein presence for detection of inflammation, cultures to check for infections of various types and tests to examine for any abnormal activation of the immune system. These tests may include immunoglobulin level determination or protein electrophoresis.

An MRI of the brain is often performed to screen for lesions suggestive of possible multiple sclerosis. The patient is presumed to have idiopathic transverse myelitis or parainfectious transverse myelitis if none of these tests are suggestive of a specific cause but other symptoms are present to suggest an infection (Lynn, 2004).

Krishnan et al. (2004) state that TM is often misdiagnosed as Guillain-Barré syndrome or acute inflammatory demyelinating polyradiculoneuropathy (AIDP) because both these conditions present with rapidly progressive sensory and motor loss. These authors posit that a pure paraplegia or paraparesis with a corresponding distribution of sensory loss may be TM and not Guillain-Barré syndrome. The latter may rather present with a gradient of motor and sensory loss affecting the lower extremities more than the upper extremities. TM is more likely to be diagnosed when weakness and sensory loss involves the upper and lower extremities equally with a distinct spinal cord level.

Diagnostic criteria made it possible to do better research on TM because scientists could better define a homogeneous group with this disorder. There are still various challenges involved in the diagnostic criteria because, although different spinal cord disorders are readily referred to as transverse myelitis,

each disorder is in actual fact very unique. For instance, TM is very different to ADEM acute disseminated encephalomyelitis (ADEM) or neuromyelitis optica (NMO) or multiple sclerosis (MS), but the diagnostic criteria still defines these as a single homogeneous group (Jeffrey, Mandler & Davis, 1993).

2.1.7 Treatment

Different stages of the disease such as acute inflammation, chronic degeneration and then repair are important when different areas of treatments are examined. One of the stages of TM that requires specific treatment is the stage of acute inflammation. This involves the infiltration of immune cells into the nervous system. These are cells that do not belong in the central nervous system and which act deleteriously on neurons and other cells. This process is complex and researching neurologists are studying the roles which these different factors play in acute injury of the nervous system (Greenberg, 2007).

Another important stage for treatment of TM is the chronic degeneration stage. After the inflammation is gone, there may be changes to the nerves which occur over time. During the acute phase there is a window of opportunity to limit the extent of damage after which the disease process changes. Finally, the body performs some repair (endogenous repair). Greenberg (2007) states that the body remyelinates itself in recovering from demyelinating diseases. Unfortunately remyelination does not restore myelin coverage completely to its original state. Remyelination is however seen as helpful in restoring myelin coverage.

Patients with TM should be offered immunomodulatory treatment such as steroids and plasmapheresis, there is however no consensus as to the most appropriate strategy yet (Krishnan et al., 2004). Intravenous steroids are often given to patients with acute TM. According to these authors there are several studies which support the effectiveness of intravenous steroids.

In a study Solumedrol was administered to five children with severe TM for three or five consecutive days and followed by oral prednisone for fourteen days. Beneficial effects were reported when compared to ten historic control patients (Baskin et al., 1990). Though the example is small, it seems to indicate that the effects of pharmaceutical medicine can be beneficial.

According to Greenberg (2007) steroids dampen the inflammatory parts of the cells (called the cytokine cascade). Cytokines are proteins that can damage the nervous system. Firstly, steroids are used to shut down their production. Secondly, steroids stop T-cells and B-cells (the two main types of lymphatic cells) from activating in the first place. Thirdly, steroids decrease the risk of immune cells going into the central nervous system. Finally, steroids actually kill off some of the deranged immune cells by starting the apoptosis of activated immune cells. Apoptosis is the self-destruction of cells; the damage is caused when the deranged immune cells are not killed off and attack the nervous system. Therefore, steroids achieve important therapeutic goals. Taking steroids over the short term is safe. Side effects may nevertheless occur and include mood changes, sleep disturbances, elevated blood sugars and slight risks of infections.

Corticosteroids have multiple mechanisms of action including anti-inflammatory activity, immunosuppressive properties and anti-proliferative actions. It is evident that the TM patients who received steroids were more likely to recover and fewer had a poor outcome. Evidence therefore suggests that intravenous steroids are somewhat effective if given in the acute phase of TM.

According to Krishnan et al. (2004) a specific steroid treated group took twenty three days to walk again. On the contrary, a group of TM patients that were not steroid treated took ninety seven days to walk again. Full recovery occurred in eighty percent of the steroid-treated group versus ten percent of the untreated group. Full motor recovery at one year was present in hundred percent of the

steroid treated group versus twenty percent of the untreated group. No serious adverse effects from the steroid treatments occurred.

Another treatment is to expose a TM patient to immunoglobulins, which are antibodies. Intravenous immunoglobulin (IVIG) is pooled antibodies from thousands of donors. When a patient is IVIG infused, he/she is exposed to a massive amount of antibodies (Greenberg, 2007). This kind of treatment is meant to neutralise and suppress pathogenic antibodies and to suppress the production of pathogenic antibodies. By flooding the body with antibodies, the cells in the body that make antibodies may get a signal to shut down and stop producing, because there are more than enough antibodies present from the intravenous immunoglobulin infusion. There is a variety of other possible ways that IVIG gets rid of pathologic antibodies, including the interruption of antigen recognition and the suppression and neutralisation of T-helper cell cytokines. Greenberg (2007) continues to explain that, in general, IVIG is very safe, but there have been reported cases of allergic reactions, headaches and kidney and lung problems.

Plasma exchange (PLEX) is often done if a patient has moderate to severe TM as well as when the patient shows little clinical improvement within five to seven days of intravenous steroids. PLEX has been shown to be effective in adults with TM and other inflammatory disorders of the central nervous system (Dodick et al., 1999). Predictors of good response to PLEX include early treatment (less than twenty days from the onset of symptoms), male gender and a clinically incomplete lesion. Dodick et al. (1999) found that PLEX may significantly improve outcomes of patients with severe (though incomplete) TM and who have not significantly improved on intravenous steroids.

Finally, immunomodulatory treatment which includes the use of intravenous cyclophosphamide should be considered for patients that do not respond to intravenous steroid therapy. Cyclophosphamide should be administered under the supervision of an experienced oncology team and care-givers should monitor the patient carefully (Krishnan et al., 2004). According to Greenberg

(2007) this is a chemo-therapeutic agent (alkylating agent) that destroys the proliferating cells of the immune system (lymphocytes). While its effects on the immune system are profound, Greenberg (2007) warns that a potential for complications exists, such as low blood counts, infections and bleeding within the bladder.

Speculations about future treatments of TM exist. According to Krishnan et al. (2004) specific immune abnormalities in patients with TM and related neuroimmunological diseases were revealed over the last few years. Autoantibodies and the presence of abnormally elevated cytokine levels in the spinal fluid of TM patients are likely to be significant. While current treatments are mainly non-specific, future treatments will more specifically target those critical immunopathogenic events in TM. For example, strategies will more effectively identify autoantibodies and the antigen to which they respond. This makes it possible to develop specific targets to block the effects of these autoantibodies (Robinson et al., 2003). To specifically alter cytokine profiles or the effects of these cytokines within the nervous system, will be a priority for future treatment.

Long term management of TM includes rehabilitative care to prevent secondary complications of immobility and to improve functional skills. It is important to begin occupational and physical therapies early during the course of recovery to prevent the inactivity related problems of skin breakdown and soft tissue contractures that lead to loss of range of motion (Kaplin, Krishnan et al.).

2.1.8 Prognosis

Minagar and Alexander (2005) state that certain TM patients experience neurological recovery irrespective of any specific therapy that has been

implemented. If recovery occurs it should start within six months. The majority of TM patients show some form of recovery within eight weeks.

Recovery may be absent, partial or complete. If no improvement occurs within the first three months significant recovery is unlikely (Berman et al., 1981). TM is generally a monophasic illness (one-time occurrence) however a small percentage of patients may suffer a recurrence, especially if there is a predisposing underlying illness.

Minagar and Alexander (2005) explain that one third of TM patients recover completely from TM. Another third recovers partly leaving them with certain problems such as spastic gait, sensory dysfunction and prominent urinary urgency and incontinence. The remaining one-third suffers permanent impairments that affect their ability to perform ordinary tasks of daily living. These patients remain wheelchair-bound or bedridden. Symptoms that are associated with poor recovery include severe back pain as an initial symptom, rapid progression to maximal symptoms within hours of onset, spinal shock and sensory disturbance up to the cervical level (Dunne, Hopkins & Shield, 1986). The presence of a certain protein, a marker of neuronal injury during the acute phase, may predict a poor recovery (Irani & Kerr, 2000).

Some TM patients recover regardless of whether specific treatment was instituted, or not. The vast majority of patients show some restoration of neurological functions within eight weeks (Dunne et al., 1986). Recovery may be rapid during the first three to six months and may continue at a slower rate, for up to two years (Irani & Kerr, 2000).

2.1.9 TM and depression

TM patients often present with symptoms of depression. Kaplin (2006) pioneered research on TM and depression and the role of cytokines and other

immune mediators. He had the first project focused on transverse myelitis and continues his effort on assessing the role of other aspects that influence the development of depression in patients with TM.

Symptoms of depression include decreased interest (or pleasure) in addition to a further total of five out of nine symptoms (for more than two weeks). These symptoms are low energy or fatigue, low mood, loss of pleasure, trouble with sleep (either increased or decreased), feelings of guilt or worthlessness, decreased concentration, loss of weight or increased weight, psychomotor retardation (or agitation) and suicidal ideation. The more symptoms, the more likely patients are to respond to treatment (Kaplin, 2006).

In a study led by Kaplin (2006) it was found that TM and depression go hand in hand. He found that depression is often an inherent symptom of TM. Kaplin (2006) compared the moods of TM patients, patients with multiple sclerosis and other chronic illnesses. He found no correlation between clinical depression and disability in TM and multiple sclerosis patients. He argues that patients with severe physical deficits are not more likely to be depressed than people with less severe physical deficits. The depression is thus not related to the level of physical disability alone. According to him depression does indeed correlate with the amount of attacks or the harshness of the attacks on the nervous system of the immune system.

Kaplin (2006) explains that when the immune chemistry has gone skewed it can trouble the brain enough to result in mood changes. He argues that cancer patients on treatment with a specific cytokine-A type of immune messenger become severely depressed. Also, the molecules can over stimulate the HPA axis, a brain pathway tied to depression. We think cytokines may mediate autoimmune depression."

Depression is not about standard sadness. Sadness is a sporadic and general experience. The level and period of the sadness is suitable to the stressor and it does not disproportionately interrupt work or social function. It is about the

lack of responsiveness. Major depression is a set of symptoms and not merely a form of severe sadness (Kaplin, 2006).

Kaplin (2006) identified the same brain patterns in patients with TM and MS. He wrote:

We now understand that the immune system is attacking the brain in transverse myelitis even though we don't see the lesions on the MRI. Evidence suggests that the activated immune system that has gotten into the brain and spinal cord is pumping out all of these chemical messengers, and those chemical messengers cause the depression.+

Depression does not correlate with sexual function, motor disability, or bladder disability or in patients with TM. A mild correlation exists that accounted for 10% of the variability in pain which indicates that the worse a TM patient's pain, the worse her/his depression scores.

2.1.10 Overview conclusion

TM is an autoimmune, neurological disease caused by focal inflammation of the spinal cord. The onset of TM is often triggered by certain infections caused by a transient abnormality in the immune system, which results in injury to a focal area of the spinal cord. Many TM patients are left with sustained disability which impacts negatively on their future functioning. Martz and Livneh (2007) remind us of the chronic sorrow which is an ongoing form of grief. This results from persistent and often intensifying losses that stem from serious, permanent chronic illnesses and disability. Depression is a common symptom of TM and it correlates with the amount of attacks or the harshness of the attacks on the nervous system of the immune system.

Another traumatic symptom of TM is pain. The next section of this chapter includes an elaborate discussion on the relevance of pain in TM.

2.2 The relevance of pain in TM

2.2.1 Introduction

"Pain is a more terrible lord of mankind than even death itself." – Dr. Albert Schweitzer (1931)

As already mentioned in chapter 1, many TM sufferers experience chronic pain and they struggle to cope with it in their daily lives.

2.2.2 Defining pain

Pain is defined in various ways. Merskey and Bogduk (1994) define pain as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Park (2011) believes that pain is the human bodyguard. Frischenschlager and Pucher (2002) state that pain is a subjective experience, which can occur in a wide range of strengths and qualities. Wallis (2005) says it is a huge challenge to define something as varied and complex as pain. Because of the subjective quality of pain, it can become an illness in itself. ~~When~~ ^{When} pain goes rogue ~~it~~ ^{it} becomes an illness in itself+(Park, 2011, p. 30).

Wallis (2005) describes chronic pain as a thief. She says:

~~It~~ ^{It} breaks into your body and robs you blind. With lightning fingers, it can take away your livelihood, your marriage, your friends, your favourite pastimes and big chunks of your personality. Left un-apprehended it will

steal your days and your nights until the world has collapsed into a cramped cell of suffering+(p. 33).

According to Park (2011):

... pain is one of life's most primitive mechanisms, by which even the simplest creature, if it has anything like a central nervous system, learns to avoid danger, stay out of bad neighbourhoods, hunker down to give itself time to heal. Pain is protective. Don't do that, it commands . and the command is usually a wise one. So this sensation we seek most to avoid is in fact one of the most essential ones for our survival+(Park 2011, p. 40).

According to Sauer, Burris and Carlson (2010) physical pain afflicts all individuals at some point in their lifetimes. Chronic pain can negatively change an individual's psychological health. Psychopathology is, according to these authors, frequently found to be co-morbid with chronic pain.

With the above in mind, pain can be seen as a protective agent, a survival mechanism, but also as an illness in itself. People need strategies to cope with pain and to manage it. Park (2011, p. 32) quotes Dr. Clifford Woolf, a neurologist at the Children's Hospital in Boston (USA) who says:

There has been a shift in thinking away from pain as only a sensory experience. Rather than targeting the suppression of pain as a symptom, the best treatment now has to be targeted at preventing pain as a disease. That insight really changes the way we understand pain.+

2.2.3 Pain management – can one control pain?

Pain management (algiatry) is the branch of medicine that employs a multidisciplinary approach for easing the suffering and improving the quality of life of individuals living with pain. Pain management professionals include medical practitioners, nurse practitioners, clinical nurse specialists, physiotherapists, clinical psychologists and occupational therapists (Main & Spanswick, 2000). Pain is usually treated with drugs such as analgesics. (The word *analgesic* comes from the Greek word *an* - "without" and *algos* - "pain").

Meyer (2007) states that the modern discipline of pain management was initiated by the book *Bonica's Management of Pain* by John Bonica (1953). Bonica discussed the complexity of pain management and the lack of skills and knowledge of healthcare providers in dealing with it. He called for better pain education. Melzack (1996) says the brain has widely distributed and parallel processing networks. It produces an excess of synapses and neurons so that we can have memory as a sort of sculpting process (David & Palladino, 1997). The new dynamic idea of the brain has a huge impact on our understanding of pain. An important theory that had a profound influence in the field of pain research and in the development of various forms of pain therapy is the Gate-control Theory of pain mechanisms, published by Melzack and Wall (1965).

According to Melzack (1996) the Gate-control Theory of pain is based on certain propositions:

- The transmission of nerve impulses from afferent fibres to spinal cord transmission (T) cells is modulated by a spinal-gating mechanism in the dorsal horn.
- The spinal-gating mechanism is influenced by the relative amount of activity in large-diameter (L) and small-diameter (S) fibres: activity in large fibres tends to inhibit transmission (closes the gate) while small-fibre activity tends to facilitate transmission (opens the gate).

- The spinal-gating mechanism is influenced by nerve impulses that descend from the brain.
- A specialised system of large-diameter, rapidly conducting fibres (the central control trigger) activates selective cognitive processes that influence, by way of descending fibres, the modulating properties of the spinal-gating mechanism.
- When the output of the spinal cord transmission (T) cells exceeds a critical level, it activates the action system . those neural areas that underlie the complex, sequential patterns of behaviour and experience, characteristic of pain.

The search for specific pain fibres and spinal cells by Melzack's critics then became almost frantic. It was not until the mid-1970s that the Gate-control Theory was presented in almost every major textbook in the biological and medical sciences.



Figure 2: Dorsal horn neuron

The modulation of inputs in the spinal dorsal horns (see Figure 2 from the Science Photo Library, sciencephoto.com retrieved on 25 September 2012) and the dynamic role of the brain in pain processes had a clinical as well as a scientific impact. Psychological factors, which were previously dismissed as reactions to pain, are now viewed as an integral part of pain processing and new avenues for pain control have opened. Physical therapists and other health care professionals who use a multitude of modulation techniques have been brought into the picture. Electrical nerve stimulation became an important modality for the treatment of chronic and acute pain (Melzack, 1996).

Melzack and Wall (1965) therefore proposed their Gate-control Theory to explain how emotions and thought processes can affect perception of pain. They presented a pain model, which was similar to the concept of a logic gate in electronics, as nerve pathways are actually electrical circuits. A certain set of initial conditions needs to be met for the pain sensation to be passed or not passed through the gate constituted by specific cells in the spine. The spine controls transmission through the spinothalamic tract to the central nervous system. (The spinothalamic tract is a sensory pathway originating in the spinal cord that transmits information to the thalamus about pain, itch, touch and temperature.)

Firstly, the structure of the gate through which pain pathways send a signal to the central nervous system, needs to be understood. There are two types of input signals, which include small nerve fibres (pain pathway fibres) and large fibres (sensory neural pathways). They are both connected to the projection cells that carry the signals through the spinothalamic tract. The projection cells are the control elements of the gate. Both types of nerve fibres (the pain receptors as well as the sensory receptors) are connected with inhibitory interneurons, which are situated in the dorsal horn of the spinal vertebrae. They can suppress transmission through the spinothalamic tract by controlling the projection cells.

Three main pain transmission scenarios need attention:

- When there is not an incoming response from both fibres, inhibitory neurons prevent transmission of signals to the central nervous system through projection cells.
- When there is a large input signal from the sensory nerves, the inhibitory neurons are activated and again prevent transmission of signals through the projection cells and no pain is felt.
- Only when there is an input signal from the small pain receptor neurons and the sensory neuron input is not large enough to activate inhibitory cells, projection cells pass the signal to the central nervous system (Melzack, 1996).

A person can distract him/herself by creating large sensory signals through thought and muscular movement and find that pain reception is reduced or even stopped due to the closing of the gate. So even consciously generated high input signals from the large nerve fibres may curtail pain. This explains why rubbing one's hand after it has been hurt, lessens the pain. The perceived intensity of pain is therefore determined by the confluence of signals from the large sensory nerve fibres and the pain receptor fibres. In this way, the Gate-control Theory tries to explain how pain perception is affected by emotions and responses from the central nervous system (Melzack, 1996).

Meyer (2007) explains that this theory integrates views of psychology and neurophysiology and states that:

... spinal transmission of pain impulses is continuously modulated by the relative activity in the small and large fibres and by descending messages from the brain that originate in the cerebral cortex and brainstem. Activation of the large fibres through pressure or low-intensity electrical currents may 'close the gate' and prevent noxious stimuli from reaching the brain+(p. 18).

The descending pain inhibitory pathway involves the action of neurotransmitters, including serotonin and noradrenalin. Meyer (2007) states

that this system is open to the benefits of cognitive-behavioural therapy and the diverse actions of anti-depressants. All the descending pathways are being influenced by the limbic system input and therefore relaxed people are likely to experience less pain than depressed and anxious people. The Gate-control Theory has been criticised as oversimplified (Stamford, 1995). Despite the criticism it provides psychologists with an understanding of how to assist people with chronic pain.

Too often pain is seen as irresolvable and an interference which one should only carry bravely. Pain signals are a valuable source of information . a warning of disease or injury, or a signal for protection+(Erickson-Klein, 1990, p. 286). The therapist, who applies the treatment, should take note of the complexity of each case. A therapist treating a patient automatically becomes a person in relationship with the patient. The manner in which congruence, warmth and empathy are expressed may assist in the process of healing (Rogers, 1942).

From the above one can conclude that a programme and techniques (such as hypnosis, medication, psychic therapy or bio-kinetics) can benefit the patient, but the manner of coping depends on personal and interpersonal encounters with significant others, medical practitioners, hospital staff, family and friends. The way in which acceptance is expressed through caring and physical touch may mean more than a prescriptive technique towards a healing process for the patient.

2.2.4 Bio-psychosocial approach

A modern paradigm of pain management moves from the biomedical approach to a much broader bio-psychosocial approach (Engel, 1980) which explains that pain mechanisms include sensory input, cognitive systems and emotional systems (Meyer, 2007). Bio+refers to the sensory input, psycho+refers to the

psychological factors and %social+ refers to the significance of interpersonal relationships and work environment that influence the perception of pain. It therefore seems clear that a person's experience of pain is multidimensional since the physical, cognitive, behavioural and emotional components of being human all play a part in the pain experience (Ogden, 2001).

Meyer (2007) explains dull pain is experienced when slow pain transmission takes place via the unmyelinated fibres and sharp pain is experienced when rapid pain transmission takes place via the myelinated fibres. Fibres, therefore, transmit painful stimuli to the cell bodies in the dorsal root ganglion and from there to the dorsal horn in the spinal cord. From there the pain stimuli go via the spinothalamic tract to the somato-sensory region in the brain where the pain is processed. Acute pain is a normal biological sign of tissue damage (Meyer, 2007). It enhances healing and serves as a symptom that should be treated.

Meyer (2007) states that depression has a profound effect on pain perception. He explains that depression lowers the pain tolerance threshold in certain circumstances. If one has acute pain and the cause is known, cognitive and emotional factors play only a small part in pain perception. If a person has had a chronic pain disorder for years, cognitive and emotional factors become much more significant and can play a major role in pain perception. Park (2011) states that people with anxiety and/or depression often report higher incidences of chronic pain. Their discomfort rises as their depression worsens. It is, therefore, argued that if depression is treated, the entire pathological cycle could be broken.

Cloud (2011) considered alternative treatments to ease chronic pain. The reason for investigating alternative treatment is that the drug-induced treatments for chronic pain often have serious side-effects, which threaten life in other ways. It can, for instance, result in damage to the liver or stomach or the patient can become addicted to the drugs. Non-drug treatments, according to

Cloud (2011) include massage, acupuncture, yoga, herbal remedies, meditation, t'ai chi, hypnosis, mindfulness-based psychotherapy and even mineral baths.

Understanding and defining something as complex as pain, continues to be a challenge for doctors, even as they try to improve their ability to treat it (Park, 2011). While most experts agree that pain is a phenomenon of the nervous system, only recently have they accepted that pain is not always traceable to a purely physical source. Patients with amputated limbs sometimes still feel pain in the missing appendage, even decades after the loss. Subjective experience of pain is nearly unlimited in its variety. With chronic pain, the problem is compounded, since in many cases there are no proximate injuries and causes to treat. What does one do about a surgical site that healed years ago, yet still causes one agony?

Not only chemical compounds, but also neural circuits may be altered in chronic-pain sufferers. Normally, a system works as a check on the amount of pain the brain can handle, so if your arm is sore and someone steps hard on your toe, your arm will temporarily feel better or less painful as all of your brain's pain attention is focused on the new insult. In chronic-pain patients, this mechanism is non-existent or faulty (Park, 2011).

2.2.5 Genetic role

Genes also play a role in the response to pain. Inherited differences in the density, type and number of receptors that detect and respond to pain, as well as the body's ability to control pain, indicate why some people feel pain more acutely than others. Dr. David Fink, director of neurology at the University of Michigan, did a gene-therapy study in which he injected chronic-pain sufferers with genes coded as natural painkillers. He aimed to boost these sufferers' levels of analgesic chemicals (Park, 2011).

The human body produces natural painkillers in the form of analgesics and opioids. These are the basis for our most powerful painkillers, including anti-inflammatory medication such as Ibuprofen and Naproxen. Whether natural or synthetic, they all work by stopping pain signals from coming along the neural highways into the spinal cord and into the brain (Park, 2011).

According to Stöppler and Shiel (2008) endorphins, on the other hand, are neurotransmitters emitting impulses within the nervous system. More than twenty types of endorphins have been demonstrated in humans.

Endorphins are most commonly released in reaction to stress and pain and they react with opiate receptors in the brain to reduce the perception of pain. As such, they act similarly to drugs such as morphine and codeine. In contrast to the opiate drugs, activation of opiate receptors by the body's endorphins does not cause addiction or dependence. Endorphin secretion leads to pain reduction, euphoria, appetite shifts, release of sex hormones and enhancement of the immune response system.

Psychology offers various interventions to control the experience of pain such as hypnotic interventions (Erickson-Klein, 1990). Some strategies involve direct suggestions for the total abolition of pain. It is seen as temporary and limited in duration and a procedure suitable for a limited number of patients. Other strategies involve permissive indirect abolition of pain through suggestions that rely on the unconscious resources (i.e. that pain serves no useful purpose) to mobilise imagination and may occur in the use of metaphors.

Through suggestions to the unconsciousness the experience of pain could be reduced, removed, substituted, reinterpreted or made controllable. The treatment focuses on the emotional content of pain as the emotional content of the sensation is diffused by the alteration of the perceived pain+ (Erickson-Klein, 1990, p. 276).

The experience of TM and the considerable amount of pain the TM patient experience, result in the obvious question how these patients deal with their

disease in their daily functioning. In the next section, various possible models for coping with disability will be discussed.

2.3 Coping models for illness and disability

2.3.1 Introduction

No research results focusing on the coping of TM patients could be found. From research done with patients with chronic illnesses or other diseases, some assumptions can be made about how patients with TM may cope in similar situations.

The sudden and unexpected appearance of disability, its onset and development constitute an acute health crisis and a turning point in an individual's life. This is exacerbated when ill health progresses into chronic disease or disability (Moos & Holahan, 2007). The intense confrontation with a severe physical disease, the extended treatment, the uncertainty and the severe personal misery, have a lasting and deep impact on the emotional experiences and identity of the patient.

Chronic illness does not only affect the person physically, it also has severe emotional and mental consequences. It, more often than not, places a heavy burden on his or her family and care-givers. It may even affect the person socially when he or she is not able to converse with ease due to the effects of the disability.

Relative adaptive tasks and coping skills, as well as determinants of adaptive coping with disability, are important to promote psychosocial recovery.

Larsen and Hummel (2009) refer to several models from the literature which can assist in understanding the process of adaptation to chronic illness. The following three of these models form suitable starting points for developing a TM Coping Model:

- the Lazarus and Folkman Model,
- the Livneh and Antonak Model and
- the Moos and Holahan Model.

The model of **Lazarus and Folkman** is a cognitive-phenomenological stress model, which views adaptation to chronic illness through adapting to stressors (Larsen and Hummel, 2009). It is a transactional model of stress and coping. Variables such as personality traits, past experiences and disease variables interact to produce coping outcomes and adaptation.

Stressors are subjected to primary appraisal to evaluate the significance of the stressor. Primary appraisal is influenced by the patient's experiences, background, personality and culture and is therefore characterised by stability across different situations (Larsen and Hummel, 2009).

The second step of the model is secondary appraisal of the situation, where the person determines what can be done about the situation. This leads to the coping strategies used to manage the stressor. The secondary appraisal is influenced by the social and environment and may be context specific. The coping strategies that are most appropriate to the situation, lead to adaptation.

Both emotion-focussed and problem-focused coping are used. Over twenty years it was found that there is a place for emotion-focused coping even though it was initially thought that emotion-focused coping yielded poor adaptation to a stressor (Larsen and Hummel, 2009).

Working from previous models, **Livneh and Antonak** organised variables associated with chronic illness into four main categories. The categories concern:

- socio-demographic factors of the person,
- disability-related variables,
- social and environmental factors and
- individual personality differences.

Livneh and Antonak argue that the adaptation process is dynamic and fluid. The adaptation status is the end result of the whole process (Larsen and Hummel, 2009).

Moos and Holahan developed a simple model that provides a framework to view adaptation. This framework is a way to conceptualise coping. Their model contains five sets of factors that are linked to the selection of appropriate coping skills and the resulted health-related outcomes such as adaptation.

The model includes three factors that influence cognitive appraisal:

- Personal resources, a broad category that includes ego, religion, intellectual ability, self-confidence and prior coping experiences and health-related experiences (Larsen and Hummel, 2009). Gender, ethnicity, age, education, optimism, autonomy, locus of control and personality are also included in this category.
- Health-related factors include the type of disability, the onset and progression of the disability, the symptoms and the prognosis. The treatment, as well as the characteristics of the disease, contributes to an appraisal of the disease-related event.
- The social and physical context includes the relationships between people with the chronic disease, but is not limited to that. The social network, family members and care-givers are all important role players in a social and physical context. Social support is related to positive adaptation in numerous chronic diseases (Larsen and Hummel, 2009).

Cognitive appraisal is the first step to decide on adaptive tasks that may be necessary. It is here where the disease is appraised as a threat or a challenge. A person who appraises a serious disease as a death sentence will make different treatment choices than another person who sees hope.

Seven adaptive tasks that can be performed following cognitive appraisal are identified by Moos and Holahan. Three of these tasks relate to health and treatment, while the remaining four tasks are more general (Larsen and Hummel, 2009). The seven tasks are:

- managing symptoms,
- managing treatment,
- forming relationships with health care workers,
- managing emotions,
- maintaining a positive self-image,
- relating to family members and friends and
- preparing for an uncertain future.

Eight categories of coping skills are identified by Moos and Holahan (Larsen and Hummel, 2009) to follow the adaptive tasks. These categories are:

- Logical analyses and the search for meaning
- Positive reappraisal
- Receiving guidance and support
- Make use of problem-solving action
- Denial and cognitive avoidance
- Resignation and acceptance
- Looking for alternative awards
- Emotional discharge

Progressing from the context through cognitive appraisal, performance of the adaptive tasks and applying coping skills health related outcomes are derived. These can be reviewed and the process can recycle as indicated in Figure 1 from Moos and Holahan (2007).

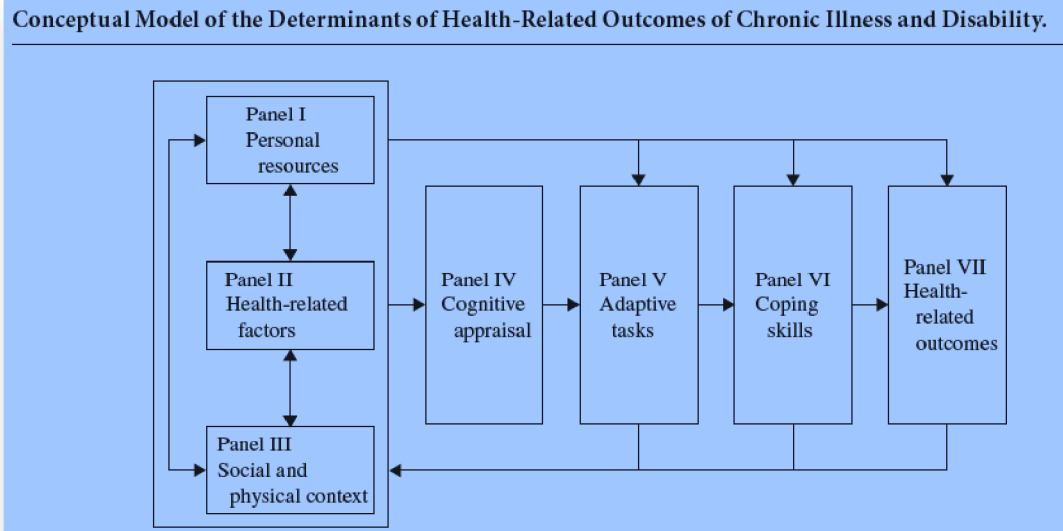


Figure 3 Moos and Holahan's model

2.3.2 Lazarus and Folkman: coping through cognitive appraisal

Folkman (2011) and Lazarus and Folkman (1984) state that psychological stress is a relationship between a person and the environment that can be potentially dangerous to the person. The researchers argue that two important processes are identified to act as the mediators to the stress response:

(a) Cognitive appraisal. This is the mental process that is utilised to judge the impact of a bad situation on a person's well-being. The level of stress that the situation creates for the individual determines how he or she will choose to cope with the stressor.

(b) Coping. Coping is the process that the person chooses to manage the demands of the stress and any associated emotions. Coping can include removing the source of stress, assessing one's personal health and well-being, as well as using social resources such as family and friends (Lazarus & Folkman, 1984).

The cognitive appraisal component is extremely important to the person identifying the level of personal harm. It can be broken down to three sub-appraisals, namely primary, secondary and re-appraisal. Primary appraisal is about assessment of the situation as being benign-positive, irrelevant or stressful. A benign-positive assessment describes situations where there is caution while the situation is seen as positive. A no-stress situation describes a situation where the person does not perceive any harm being done to them and a stressful assessment indicates possible challenge, harm or damage. A primary assessment of stress can take the form of fear and anger (Lazarus & Folkman, 1984).

A secondary appraisal is about thought processes and decisions regarding a possible use of available resources to ease the threat. Specific coping strategies stem from secondary appraisal. Primary and secondary appraisal is interrelated in the development of the specific emotional outcome.

Re-appraisal is about an evaluation of the circumstances based on new information provided by the environment or the person's emotional reaction and coping strategy (Lazarus & Folkman, 1984).

Lazarus and Folkman (1984) defined coping as dynamic cognitive and behavioural efforts to manage particular external and/or internal demands. Demands that require more resources, than are readily available, are viewed as taxing to a person. According to Lazarus and Folkman (1984) coping strategies take on one of two forms, namely emotion-focused coping or problem-focused coping and the strategies are not primarily determined by personality traits, but are situation dependent.

Emotion-focused coping strategies are directed toward decreasing emotional distress. These tactics include such efforts as distancing, avoiding, selective attention, blaming, minimizing, wishful thinking, venting emotions, seeking social support, exercising, and meditating. Similar to the cognitive strategies identified in problem-focused coping efforts, changing how an encounter is construed without changing the objective situation is equivalent to reappraisal.

The following are common examples: %o decided that something a lot worse could have happened+or %ojust decided there are more important things in life.+ Unlike problem-focused strategies, emotion-focused strategies do not change the meaning of a situation directly. For example, doing vigorous exercise or meditating may help an individual reappraise the meaning of a situation, but the activity does not directly change the meaning. Emotion-focused coping is the more common form of coping used when events are not changeable (Lazarus & Folkman, 1984).

Emotion-focused coping does not concentrate on the external environment, but rather on finding appropriate internal emotional responses. A person's attempts to control their emotional reaction usually include control by means of avoidance or through thought processes (Lazarus & Folkman, 1984).

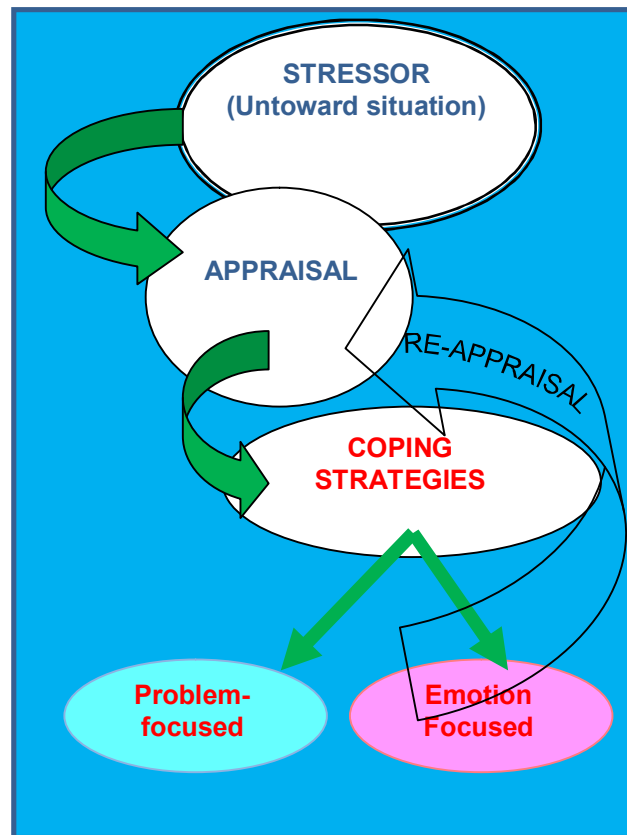


Figure 4: Theoretical framework

Lazarus and Folkman (1984) continue to explain that in problem-focused coping, direct action is used in an attempt to change the cause of stress. The theory of emotion-focused and problem-focused coping enabled Lazarus and Folkman (1987) to further their study on the empirical relationship between mediating, outcome and antecedent variables. Figure 1, which illustrates this process, has been developed in this study based on a similar representation by these authors.

Problem-focused coping strategies are used in coping with a stressful situation by confronting the problem and making efforts to actively resolve it. Problem focused coping strategies include defining the problem, generating alternative solutions learning new skills, weighing alternatives and choosing among them and shifting goals to meet demands (Lazarus & Folkman, 1984; Parker & Endler, 1992).

Lazarus (1966) and Lazarus and Folkman (1984) summarize a large body of empirical evidence supporting the distinction between emotion (palliative) and problem-focused (direct-action) coping. In addition, the evidence indicates that everyone uses both types of strategies to deal with stressful encounters or troublesome external or internal demands.

Folkman (1997) proposed an extension of the model regarding the theoretical understanding of coping based on her work in studying AIDS-related care-giving. Her study involved measurement of multiple variables of psychological state (depressive symptomatology, positive states, and positive and negative affect), coping, and religious or spiritual beliefs and activities. Each care-giver participant was interviewed twice. Although participants reported a high level of negative psychological states as expected, they also reported high levels of positive affect.

Interestingly, the interview data, when examined along with quantitative analyses, revealed that the coping strategies associated with positive psychological states had a common theme, namely the finding of positive meaning. "Positive reappraisal, problem-focused coping, spiritual beliefs and practices, and infusing ordinary events with positive meaning all involve the activation of beliefs, values, or goals that help define the positive significance of events+(Folkman 1997, p. 1215).

Folkman (1997) cites many studies that support her conclusion that finding positive meaning in a stressful situation is linked to the experience of well-being. Research based on stress is applied in the field of chronic illness with the assumption that there are similarities between coping with stress and coping with illness. Stress is complex, expensive and debilitating to society.

According to Lazarus and Folkman (1987) stress mainly addresses cognitive appraisals, negative person-environment relationships and emotional responses, including fear and anger, because it falls under the wide category of emotion. As part of this wide category, they apply a meta-theoretical approach to the concept of stress. Using the meta-theoretical approach, Lazarus and Folkman (1987) proposed three themes of emotion:

- transaction,
- process and
- emotion as an interdependent system of variables.

2.3.2.1 *Transactional nature of model*

Lazarus and Folkman (1987) set out that understanding the essential point of transaction involves a congruous approach and cannot merely acquire the standpoint of the person or the environment. Such a congruous approach consists of specific environmental characteristics as well as a particular type of person when exposed to the specific environmental characteristics.

2.3.2.2 Process with regard to stress

Lazarus and Folkman (1987) explain process with regard to stress as relating to change over time or across situations. The desire to change or cope with unwanted outcomes caused by stress discharges negative emotions which give rise to process.

Coping is significant when discussing stress because it is directly related to stress. Lazarus and Folkman (1987) describe coping as a comparative process where the events of one moment are compared to those of another.

Lazarus (1966) and Lazarus and Folkman (1984) link stress-related variables to health-related outcomes. The constructs in their transactional model jointly affect adaptational outcomes. The theorists propose three types of adaptational outcomes: (a) functioning in work and social living, (b) morale or life satisfaction, and (c) somatic health.

They view the concept of health to broadly encompass physical, psychological and social functioning. Physical functioning considers the presence of somatic conditions such as illness, while psychological functioning involves the cognitive functional ability and morale . how people feel about themselves and their lives. Social functioning examines interaction between people and/or groups of people.

2.3.2.3 Emotional nature of model

They continue by explaining that emotion cannot be expressly described as being an environmental stimuli or being a response to stimuli but depends rather on a variety of mediating variables which are environmental antecedents including constraints, demands and resources.

Examples of these personal antecedents are personal beliefs, values, self-esteem and trust. Further examples include mediating processes such as

appraisal of the stress situation. The short term effects of physiological changes and the long-term effects of psychological well-being (Lazarus & Folkman, 1987) are personal antecedents too.

2.3.3 Ways of coping with chronic disease

2.3.3.1 *Maintaining a positive self-image*

It is important to preserve a healthy self-image and to maintain a sense of mastery and some form of competence. Physical changes in appearance such as paralysis, weakness and difficulty with movement should be integrated into a new, positive self-image. Where applicable the idea of physical attractiveness should be revised and therefore a shift in personal values must be done.

2.3.3.2 *Managing emotions*

This set of tasks involves maintaining emotional balance during the onset of TM. Feelings of inadequacy, anger, anxiety, fear, sadness and isolation are normal during a health crisis. The task is to employ coping strategies such as resilience, hope, as sense of humour, benefit-finding and religion or spirituality.

2.3.3.3 *Preparing for an uncertain future*

If physical strength and the ability to walk, play sport and be physically independent are lost, these losses should be acknowledged and mourned. Significant losses are threatening and cause an uncertain future. While some TM patients grieve the permanent loss of a certain level of mobility, they hope that new treatment and cures may be beneficial.

According to Holland and Ward (1966) illness is regarded as a physical [condition], yet many other factors influence its course and outcome and sick people are psychologically very vulnerable (p. 358). Factors that influence the course and outcome of illness are inter alia a person's personality structure, the emotional reaction of family, the relationship with the medical staff and the patient's friends. Holland and Ward (1966) believe that anxiety regarding the perception of the degree of the illness affects the patient's present and future ability to work and, therefore, his or her financial security.

2.3.4 Moos and Hollohan's model for coping with illness

Moos and Hollohan (2007) developed a model for coping with illness. They identified the following strategies as part of the model:

- Logical analysis and the search for meaning,
- cognitive restructuring,
- positive re-appraisal,
- seeking guidance and support,
- taking problem-solving action,
- cognitive avoidance or denial,
- acceptance and resignation,
- seeking alternative rewards and
- emotional discharge.

A description of these strategies will now be given.

2.3.4.1 *Logical analysis and the search for meaning*

Coping skills used in the search for meaning entail dissecting a problem into manageable parts by picturing past bad experiences. A person remembers bad experiences to use associated coping skills in the challenge situation. It is about psychologically rehearsing probable measures and their likely consequences, as well as confirming one's own confidence by recalling

previous successes in times of difficulty (Moos & Holahan, 2007). These skills include chronically ill patients' efforts to learn more about their disease and its likely stages of development. They can also learn what they can do through medical involvement and lifestyle changes to cope with their symptoms.

2.3.4.2 Cognitive restructuring

Cognitive restructuring (positive re-appraisal) covers the cognitive strategies by which a person accepts the basic reality of this disease while viewing it from the most favourable angle. These strategies include:

- thinking of oneself as still privileged compared to some other people in important respects,
- altering one's priorities and values to match the changed reality,
- reminding oneself that the situation is not as testing as it could have been and
- focusing on the realisation that something good can possibly surface from one's disease.

A disease might help a patient to redirect his or her life (Moos & Holahan, 2007).

2.3.4.3 Seeking guidance and support

Guidance and support are garnered to obtain information about the disease, the different treatment measures and their likely outcomes. These skills are frequently used in conjunction with logical analyses. Individuals with chronic illnesses will, for instance, try to reinstate a sense of control by mentally preparing themselves to conquer expected problems.

They will do so by working through the steps involved, as well as learning about demands that are being made on them. This set of coping skills utilises emotional encouragement and actual support from friends, care-givers and family (Moos & Holahan, 2007).

2.3.4.4 *Taking problem-solving action*

Problem-solving skills are used to deal directly with a situation by, for instance, learning specific healthcare procedures. These skills include the management of the disease and symptoms and physically redesigning a home to accommodate declining mobility. They also include the strategy of progressive desensitisation whereby individuals in wheelchairs or with disfigurement gradually expose themselves socially to desensitise themselves to their own, as well as other people's reactions (Moos & Holahan, 2007).

2.3.4.5 *Cognitive avoidance or denial*

Avoidance and *denial* are techniques used to minimise the gravity of a crisis. These strategies may initially be directed at the symptoms. After diagnosis, the strategies may be aimed at the significance of an illness (e.g. an individual with a fatal condition consults one doctor after another looking for an alternative diagnosis). Cognitive avoidance can involve the potential consequences of an illness such as the initial denial that often occurs after diagnosis of a stroke. These self-protective responses can temporarily protect an individual from feeling emotionally overwhelmed and can provide time to garner other personal coping resources (Moos & Holahan, 2007).

Mental health professionals often aim to eliminate denial because it may be harmful (Barlow & Durand, 1999). Denial is, however, not harmful in all cases.

It acts as a shock-absorber when a person experiences initial anxiety upon being diagnosed with a serious physical illness. It bolsters endurance. The person can develop other coping strategies at a later stage. Denial is a valuable coping strategy when used at the right time. The timing, therefore, proves to be important for the effectiveness of this coping strategy.

2.3.4.6 *Acceptance and resignation*

Acceptance is required in coming to terms with the reality of a health condition and prognosis and in acknowledging that the overall circumstances cannot be altered. It is hard to strike a reasonable balance between acceptance with continued hope and acceptance with *resignation*, while rapid changes occur in the course of disability (Moos & Holahan, 2007). Acceptance may involve admitting an ongoing health problem, giving up unproductive efforts to control symptoms and committing oneself to living, as satisfying a life as possible. As death approaches, a conscious decision to accept the inevitable helps to mitigate distress and free the patient to search for deeper meaning in her/his circumstances.

2.3.4.7 *Seeking alternative rewards*

Alternative avenues may be sought to replace the losses which stems from a health condition. Changing activities and creating new sources of satisfaction are coping responses that entail redirecting one's energies towards new goals when an original goal becomes unattainable (Moos & Holahan, 2007). A patient might, for example, redirect his or her activities towards helping others with the same disorder by sharing information, acting as a role model, or raising funds to find a cure. These activities give patients a constructive involvement to look forward to and provide a realistic opportunity to achieve a goal they consider as meaningful.

2.3.4.8 *Emotional discharge*

Emotional discharge may be achieved by openly venting feelings of anger or despair, crying or screaming in protest at news of a fateful prognosis and using jokes and gallows' humour to help allay distress (Moos & Holahan, 2007). It may also entail "acting out" by not complying with a treatment regimen, as well as behaviour that may temporarily reduce tension, such as when an individual on dialysis goes on eating binges. Such behaviour may involve a temporary failure of affective regulation, as individuals may alternate between emotional control and emotional discharge.

2.3.4.9 *Using combinations of coping strategies*

The mentioned strategies cover the most common types of coping skills employed to deal with a health crises. Coping skills are seldom used singly or exclusively (Moos & Holahan, 2007). A patient may deny or minimise the seriousness of a crisis when talking to a family member, may seek information about a prognosis from a physician and may openly vent anger and despair to a friend. An ongoing health condition presents a variety of related tasks and requires a combination or sequence of coping skills.

2.4 Chapter conclusion

In this chapter, the occurrence, symptoms, causes, diagnosis, possible treatments and prognosis of TM, were discussed. A conclusion was given that TM patients are left with sustained disability which impact negatively on their future functioning.

After an extensive discussion on TM, the relevance of pain and the role it plays in TM was explored. Definitions of pain, a bio-psychosocial approach to pain as well as the genetic role of pain was brought to bear. Some strategies in pain management were highlighted. A conceptual strategy to handling stress in

general and a summary of contemporary knowledge and theories regarding coping with chronic illness were given as background and framework.

In chapter 3, an in-depth theoretical framework on positive psychology is discussed. An extensive theoretical discussion is presented regarding seven established constructs of positive psychology that will be used in the research. These are positive coping, searching for meaning, benefit finding, hope, sense of humour, resilience and religion and spirituality.

Chapter 3

Theoretical framework

3.1 Introduction

Psychology, as an emerging science, developed as the discipline studying mental dysfunction and illness. Psychology as a field was understood as *the study of the illness of the mind* (Basson, Fouche, Saaiman & van Eeden, 2001, p. 4). Extensive research regarding individual mental abnormalities brought about highly developed knowledge of deficiencies and vulnerabilities of the mind. From this point of departure the discipline built concomitant professional credibility. In the process very little knowledge was recorded regarding healthy mental abilities and strengths (Wissing, 2000) and, therefore, potentially fertile soil remained uncultivated.

Since World War II, the treatment of mental illness, the alleviation of psychological suffering and the repair of psychological damage attained further dominance in the field of psychology and psychiatry. Alessandri, Heiden and Dunbar-Welter (1995) explain that combatants suffered unprecedented psychological trauma, termed *shell shock*, during World War II. Reisman (1991) states that psychologists were then called upon to treat this condition as physicians, including psychiatrists, were over-extended in treating physical injuries. *Shell shock* was later named *post traumatic stress* to indicate a general condition after severe trauma.

During World War II female psychologists formed a National Counsel of Women Psychologists (Compas & Gotlib, 2002). These female psychologistsq main purpose was to help societies and communities deal specifically with the stressors of war. Times of intense conflict leave limited room for psychological interest in the good life, the good things in life and the aspects of life that make it worth living. The predominant medical trend of viewing people primarily in terms of pathology also permeated the field of psychology. Psychology, probably because of a legacy of wartime suffering, focused on human failures and disorders.

Even today, the major emphasis within the field of psychology is on pathology and negative feelings (Seligman & Csikszentmihalyi, 2000). Avia (1997) posits that there are several reasons why negative emotions attract research focus. According to her, the roles played by negative emotions are thought to be genetically and phylogenetically, more important for survival+ (Avia, 1997, p. 35). Not only have human emotions been the target of this pathologising approach but this predilection has been directed at human cognition and behaviour as well.

Psychology has, therefore, been developed as a field operating primarily within a pathogenic paradigm (Strümpfer, 1990). Heather (1976) argues that when dealing with human beings, the field of medicine also reflects the focus on pathology. Viewing people in terms of possible pathology is, therefore, a predominating and hitherto contemporary trend. The Diagnostic and Statistical Manual of Mental Disorders . IV (DSM-IV) of the American Psychiatric Association (APA, 1994) also emphasises pathology. Classic psychology focused on human failings and deficits in a bid to be a predictable, serviceable science based on the medical model. In the process the discipline gained respect from the therapy purchasing community. Even though Battista and Almond (1973) already urged for a psychology of potential and growth, the focus still remained on pathology.

3.2 Towards the development of positive psychology

Since 1999, a relatively new view of psychology emerged. Seligman (2003) refers to the new trend, with less focus on pathology, as positive psychology.

Strümpfer (2005) explains that academics and practitioners realised the need for additional research and knowledge about individuals' inner strengths, growth, adaptive resources and overall well-being. This eventually led to the development of positive psychology. Strümpfer (2005) notes that the idea of a discipline of positive psychology is not exactly novel. Maslow already touched on the subject of positive psychology in the mid-1950s (Resnick, Warmoth & Serlin, 2001). As a humanistic psychologist, he focused on human actualisation and potential. He viewed people holistically and not with regard to their deficits only.

Resnick et al. (2001, p. 77) proposed that the conscious experience of creative, healthy persons should be at the centre of psychological investigation. Humanistic psychologists focused on comprehending an individual's conscious experience through that individual's own phenomenological truth. The important key factor here is the focus that was placed on fully functioning people. The search for illness was no longer the main focus.

According to Taylor (2001) several other theorists played an important role in the development of the movement of positive psychology. Taylor (2001) mentions Murray who, in the 1930s, said that psychology needed to attend to joyful, positive and fruitful experiences in the lives of people.

Positive psychology is restoring balance after psychopathology was over-emphasised for many years. Avia (1997) explains that positive emotions are very important to an individual's well-being. Being in a good mood, feeling optimistic and satisfied with life and experiencing well-being and happiness are not only desirable but, most likely, essential for a healthy personality (p. 33).

Table 1: Flash representation of classical 20th century contributions in establishing the discipline of positive psychology

CONTRIBUTOR	KEYWORD SUMMARY OF CONTRIBUTIONS			
William James (1842 . 1910)	Religious experience to add zest to life	Mysticism (forerunner to flow concept and Maslow's peak experiences)	A melioristic universe where the world could be made a better place by human effort	The concept of hope
Robert Assagioli (1888 . 1974)	Psychosynthesis . orientation towards giftedness and health			
Carl Jung (1875 . 1961)	Psychology of consciousness: Introversion and extraversion	Total unity with self as the centre	Individuation towards self-realisation	
Lewis Terman (1877 . 1956)	Terman-life cycle study . research on gifted children	Marital happiness		
Alfred Adler (1870 . 1937)	Creative self	Striving for superiority		
Charlotte Bühler (1893 . 1974)	Intentionality . an attempt to give meaning to life	5 Stage structure of normal human development		
Kurt Goldstein (1878 . 1965)	Drive to self actualisation and self-realisation	Creative expansion		
Gordon Allport (1877 . 1956)	Mastery and competence	Tolerant personality	Mature personality	Psychology and religion
Henry Murray (1893 . 1988)	Mythology	Psychogenic needs	Organismic study of normal functioning	
Carl Rogers (1902 . 1988)	Unconditional positive regard	Fully functioning personality & moral responsibility	Actualising tendency towards optimal functioning	Influenced society management and even national and international politics
Victor Frankl (1905 . 1997)	Logotherapy	Finding meaning in suffering	The will to self-transcendence	
Donald W MacKinnon (1903 . 1987)	Positive personality functioning			
Frank Barron (1922 . 2002)	Personal soundness	Psychological validity	Creativity in highly effective individuals	
Erik Erikson (1902 . 1994)	Interpersonal mutuality	Theory on child and human development . 8 stages		
Harry Stack Sullivan (1892 . 1949)	Personality results from interpersonal relationships			
Abraham Maslow (1908 . 1970)	Growth needs and self-actualisation	The term: Positive Psychology	Spirituality . peak experiences, transcendent ecstasy, mystical experiences	Being values and active will to health
Marie Jahoda (1907 . 2001)	Human inner nature			
Robert White (Harvard University)	Six Criteria for positive mental health	Efficacy . the attainment of competence		
Douglas McGregor (1906 . 1964)	Effective drive of novelty	Theory X and Theory Y in the workplace		
David Bakan (1921 . 2004)	Self-direction and self-control	Psycho-therapy		
Mihaly Csikszentmihalyi (1934 .)	Agency and communion	Flow		
Aaron Antonovsky (1923 . 1994)	Optimal experiences from creativity, religion, games, sport, reading, hobbies, meditation	Salutogenesis . origins of health	Sense of Coherence Model	
Edward Deci (University of Rochester)	Resistance resources	Theory of Intrinsic motivation	Competence	Self-motivation
Susana Kobasa (University of Chicago)	Self-determination and personality hardiness	Existentialism	Control	Challenge and commitment

Table 1 serves to demonstrate that the work of many prominent theorists lead to the emergence of positive psychology. It was endeavoured to create a single page overview relating prominent contributors to theory keywords. Please note that the table does not list contributors in alphabetic order or in order of birth, but in the loosely chronological order in which major contributions received international attention.

3.3 Defining positive psychology

Martin Seligman says that psychology is not only the study of damage and weakness. Psychology is also the study of virtue and strength. Treatment is not merely to repair what is broken; it is also about promoting what is best within people (Seligman, 2003).

Positive psychology is characterised by Seligman and Csikszentmihalyi (2000, p. 7) as a science of positive subjective experience, positive traits and positive institutions. The idea, according to Seligman and Csikszentmihalyi (2000), is not that positive psychology should ever replace classic psychology, but that it complements and extends it.

3.3.1 Definition

Positive psychology can be defined as the scientific study of ordinary, positive, subjective human strengths, virtues, experiences and functioning (Seligman & Csikszentmihalyi, 2000; Sheldon & King, 2001). Peterson (2009) states that positive psychology cannot tell people what to value. Positive psychology can certainly shed light on the *what* and the *why* of whatever they value. New knowledge can offer people new options in living their lives.

According to Peterson (2009), positive psychology is concerned about four major topics, namely:

- positive relationships,
- positive experiences,
- enduring psychological characteristics and
- positive institutions like schools, youth development programmes and families.

3.4 Positive psychology viewed on a subjective level

Positive psychology can be viewed on a subjective level, namely optimism, happiness, hope, flow, well-being, satisfaction and contentment. At the individual level, it refers to interpersonal skill, capacity for love, perseverance, wisdom, forgiveness, future mindedness, high talent and spirituality. At a group level, it is related to work ethic, altruism, responsibility, civility, tolerance, moderation, nurturance and civic virtues (Seligman & Csikszentmihalyi, 2000). According to Sheldon and King (2001), positive psychology is simply psychology. It is merely a scientific study of human beings virtues and strengths. Joseph and Linley (2004) conclude that positive psychology serves as a beacon under which people working to assist others in their pursuit of a good life may gather+(p. 143).

Lopez and Snyder (2004) argue that positive psychology is about subjective experiences such as happiness, hope, faith, optimism, sensual pleasures, joy, well-being and satisfaction. Gable and Haidt (2005) note that positive psychology is the study of processes and conditions that contribute to the optimal functioning of institutions, groups and people. Sheldon and King (2001) define positive psychology as a scientific study of human virtues and strengths.

According to Resnick, Warmoth and Serlin (2001) positive psychologists view the concept of human potential as a worthy topic to study. Csikszentmihalyi (2009) made an important contribution by observing that positive psychology should not be predominantly concerned with the positive feelings of people regarding their

situations, but rather with ways for people to flourish in the different domains of their lives.

An interesting approach is the enabling, indirect one. Csikszentmihalyi (2009) posits that psychologists use this approach in order to determine what the important conditions are to make individuals more optimistic, happy and satisfied. The idea is to understand the psychology that makes people feel good about their lives in an indirect way. An indirect approach to positive psychology would therefore entail the fostering of optimism and happiness by cultivating enabling social systems. Such social systems may, inter alia, be characterised by better jobs and better political structures.

3.5 Positive contribution to the survival of our species

Csikszentmihalyi (2009) furthermore states that it is clear that leading a more meaningful life is not the only or most important goal of positive psychology. A more ambitious goal is for psychology to make a positive contribution to the survival of our species.

One of the basic principles of all religions is that human beings have an obligation toward more than just themselves. Csikszentmihalyi (2009) explains that religion not only sensitise human beings to a responsibility for own actions, but also for the important consequences individual actions have for a larger scope of life. He stresses the importance of a fresh view on what it means to be human. According to him, as a species, we have been quite schizophrenic about our own identity. On the one hand, people view themselves as organisms run by lust and greed, governed by genes that have no interest in destiny or replication; on the other hand, people have thought of themselves as masters of the universe and as the ultimate goal of creation. Neither viewing human beings as selfish genetic robots nor viewing them as supreme is realistic or constructive.

Csikszentmihalyi (2009) would like to think of human beings as the cutting edge in the evolution of complexity. He also says that after a hundred years of deflating old certainties, social sciences have a more benign view of human beings. He posits that the mentioned deflating started with the biological writings of Darwin (1972), which inspired Spencer (2009) who reduced human beings to the puppets of property relations. Freud (1920) viewed human beings as slaves to sexual tendencies, which are necessary for reproduction. Nowadays, a tendency developed to draw religious insights together with evolutionary biology. Recent writings contribute to the knowledge that humans need more than sex and greed in order to survive (Csikszentmihalyi, 2009). Spiritual empathy with the universe, cooperation and altruism are also important factors for survival.

Positive psychology focuses on a large scope of what makes life worth living (Seligman & Csikszentmihalyi, 2000). McCullough and Snyder (2000) describe strengths of character, positive experiences and a satisfied life as amongst the central areas of interest of positive psychology. Character strengths are described as positive character traits that reflect an individual's thoughts, feelings and behaviours. These traits become clear in various degrees and they can be measured by Peterson and Seligman's *values in action (VIA) classification of strengths* (2004).

In this study, attention is focused on certain specific positive psychological constructs and their significance for physical well-being. A key topic of this study is the recognition of how positive psychological constructs influence physical health. The researcher intends to discover how TM patients use positive characteristics and strategies to cope with their disease. Eventually the researcher wants to equip these patients with strategies to deal with their illness better.

3.6 Antonovsky's contributions

Antonovsky (1979) introduced the construct *salutogenesis* in order to focus on the sources of mental health. The word *salutogenesis* originates from the Latin word

salus which means health and the Greek word *genesis* which means origin. This term was coined by Antonovsky who studied stress management and well-being (Antonovsky, 1987). He observed that, while stress is universal, not all people have bad health outcomes in response to stress. To the contrary, many people experience good health despite their exposure to possible disabling stress factors.

3.6.1 Antonovsky's theory of salutogenesis

Antonovsky's ideas about salutogenesis develop from his observation of Jewish women's experiences in the concentration camps during World War II. Many of these women stayed healthy despite the terrible circumstances they were in. The construct *sense of coherence* was introduced by the Antonovsky, more than twenty years ago. It claimed that the way people experience their lives seems to influence their health positively. Antonovsky's *sense of coherence* explains the manner in which people stay healthy in stressful situations and how they can even improve their health in times of adversity.

Strümpfer (1995) preferred the term *fortigenesis* to describe positive behaviour, rather than *salutogenesis*. The following words, namely fort (which means a fortified place), fortitude (which means courage and strength in times of adversity or pain) and fortify (which means endurance or vigour or to strengthen morally or mentally or to employ physical strength) have the same origin. *Fortigenesis* emerged from the Latin word *fortis* (which means strong) and is more descriptive than the term *salutogenesis*. *Fortigenesis* is a more embracing, holistic term that emphasises the origins of mental strength. Strümpfer (1995) refers to Rotter's locus of control, the self-efficacy theory of Bandura and Kobasa's concept of hardy personality in illustrating the holistic viewpoint. Antonovsky (1979) named these constructs *generalised resistance resources* (GRRs) that help an individual to deal with stress.

Antonovsky (1979) defined *generalised resistance resources* as characteristics of the primary group, or the environment, or the person that can mediate efficient stress management. Cognitive, interpersonal-relational, biochemical, valuative-attitudinal,

emotional, physical and artifactual-material traits protect people against psychological stressors (Antonovsky, 1979). According to him, physical health, a sense of coherence and feelings of well-being are established when a significant amount of GRRs are present. Sense of coherence is explained by Antonovsky (1979) as enduring, dynamic feelings of confidence of which the extent is expressed through a global orientation.

Positive psychology focuses on locating and developing social resources and personal adaptive tendencies, which can contribute to effective coping behaviour and personal growth (Breed, 1997). This study addresses and identifies coping resources in order to encourage better coping behaviour by TM patients.

The salutogenic paradigm was developed from several personality theories. Growth, wellness and optimal psychological functioning were emphasised (Antonovsky, 1987; Strümpfer, 1995). Numerous new positive psychology constructs were added to this body of knowledge from the year 2000 onwards (Carr, 2004; Fredrickson, 2001; Snyder & Lopez, 2002). Constructs such as coping (Somerfield & McCrae, 2000), internal locus of control (Strümpfer, 1990), well-being (Lyubomirsky, 2001), positive affect (Folkman & Moskowitz, 2000), courage, gratitude (Lopez & Snyder, 2003), creativity and flow (Nakamura & Csikszentmihalyi, 2001; Simonton, 2000); resilience (Masten, 2001), sense of humour (Fredrickson, 2001), emotional intelligence (Lopez & Snyder, 2003), faith and optimism (Peterson, 2006; Schneider, 2001) are included in positive psychology.

3.7 Some influential theoretical developments

Diener, Eunkook, Robert and Smith (1999) state that subjective well-being is a broad category of phenomena that includes people's emotional responses, domain satisfactions and global judgement of life satisfaction+ (p. 277). There are three related human needs that are investigated by the self-determination theory:

- the need to belong,
- the need for competence and
- the need for autonomy.

According to Ryan and Deci (2000), personal well-being and social development are optimised when these needs are satisfied. Individuals with these needs satisfied are able to fulfil their potential. They are intrinsically motivated and are able to seek progressively greater challenges. Ryan and Deci (2001) make a prominent distinction between psychological well-being and subjective well-being.

Diener (1984) describes subjective well-being as a subjective evaluation of an individual's life. Psychological well-being is explained as an existential matter. Ryff (1989) posits that psychological well-being is about positive relationships, self-acceptance, personal growth, autonomy and environmental mastery. Waterman (1993) notes that subjective well-being and psychological well-being have different psychological and biological patterns and are dissociated with each other.

Measuring on a dual scale of subjective and psychological well-being Keyes, Shmotkin, & Ryff (2002) contra-intuitively found that 45% of the participants in one of his studies scored low on subjective well-being and high on psychological well-being, or vice versa. The human desire for a sound mind in a healthy body evidently neither obviates the possibility of facing psychological problems despite being in good physical health nor the desirability of maintaining a sound mind despite physiological challenges. Psychological well-being has recently become a main focus of the clinical treatment of depression (Duckworth, Steen & Seligman, 2005; Fava, 1999).

The work of Strümpfer (1990, 1995, 2004, 2005) is especially intriguing as his fortigenic theories are invaluable in understanding people's strengths and resources (Snyder & Lopez, 2005; Strümpfer, 1995; Wissing & Van Eeden, 2002). The researcher used this knowledge over a period of ten years (and counting) to discover pathways for supporting TM patients. From practical experience and discussions with TM patients over this time, certain predominant positive psychological constructs emerged. The seven established constructs are introduced below.

3.8 The seven established constructs

3.8.1 Introduction

The various themes that emerge from the collected data reflect seven established constructs from the literature as shown below.

The seven constructs are:

- Positive coping
- Search for meaning
- Benefit finding
- Hope
- Sense of humour
- Resilience
- Religion and spirituality

Positive coping refers to the tenacity and ability to overcome critical events that challenge a person. Positive emotions are connected to positive coping because positive emotions stem from the ability to find positive meaning (Fredrickson, 2005). It is nevertheless beneficial to derive the positive meaning from a primarily problem-focused coping strategy as this, according to Lazarus and Folkman (1984), yields far more positive results than primarily emotion-focused coping.

The **Search for meaning** is an important element in coping with adversity such as depression, loneliness, post-traumatic stress disorder and physical health problems such as chronic illness and coping. Multiple sources of meaning in life protect people against feelings of meaninglessness. The four needs for meaning and the active process (Baumeister & Vohs, 2005) of search for are discussed under the appropriate heading below.

Benefit-finding is the ability to derive positive personal benefit from adverse situations. Over the past ten years researchers redirect their attention from the

negative impact of traumatic events towards the positive. Literature indicating how patients with serious illnesses have found and may find positive ways to cope with their adversity is growing accordingly.

Hope might be, according to Erikson (1964), the most indispensable virtue inherent in being alive. The concept of hope, definitions of hope and the cognitive side of hope gets more attention below. The importance of a perceived probability of achieving a goal and its relation to hope as well as Viktor Frankl's disposition on hope is explained. The importance of religious affiliation as well as hope and coping is discussed. The full hope model as well as hope theory is investigated.

Humour has beneficial coping effects on people during times of trial (Adamle & Turkoski, 2006). The term *humour* is analysed and the stress-relieving, pain-reducing and immunity-building qualities of humour are investigated.

Resilience interacts with all the other constructs in assisting the individual to psychologically bounce back to (at least) one's usual state of functioning in times of adversity. Definitions of resilience, positive emotionality and resilience and multi-systemic occurrence are set out. Kralik, Van Loon and Visetin (2006) state that resilience is a key factor in the transitional process of learning to adapt to a chronic illness.

Religion and spirituality is described as the search for significance in ways related to the sacred (Pargament, 1997, p. 32). Religion is defined below and explained as functioning at three different levels. The interesting inter-relatedness between religious pathways is examined. A positive correlation between religion, physical health and mental health is debated. Religious coping as neither a problem-focused nor an emotion-focused strategy is explored. Finally it is investigated whether coping and religion are two separable concepts.

3.8.2 Positive coping

"Coping is the pursuit of mastery and human growth." Ziedner and Saklofske (1996, p. 506).

Coping can be defined as an effort to manage and overcome demands and critical events that pose a challenge, threat, harm, loss, or benefit to a person (Schwarzer & Knoll, 2004). The term coping has often been used, in a more narrow sense, as a response required of an organism to adapt to adverse circumstances. According to Schwarzer and Knoll (2004), the conceptualisation of coping is broadening, though. It now also includes self-regulated goal attainment strategies as well as personal growth.

The constructs of adjustment and adaptation play the main role in studying coping effectiveness. Adaptation refers, according to Lazarus and Folkman (1984), to the processes that are used to manage environmental demands. In 1933 Freud described several defence mechanisms such as projection, reaction formation, sublimation, displacement, suppression, repression, regression and rationalisation that were unconsciously triggered to discharge the stress that came from the id-super ego conflicts. Current psychological research views coping as a conscious, active process that exploits resources such as stress management experience. Coping is, according to Ziedner and Saklofske (1996), more than simple adjustment. According to them, functional coping behaviour buffers the immediate impact of stress and ensures a sense of self-worth and wholeness with one's past and anticipated future+(p. 506).

Coping can occur as a response to an event or in anticipation of upcoming demands, but it can also involve a pro-active approach to self-imposed goals and challenges. Many attempts have been made to classify coping behaviours into a more parsimonious set of coping dimensions. One way to cope with adversity is to create and enhance positive emotions.

Strümpfer (2004) refers to Fredrickson who researched the benefits of positive emotions. Fredrickson describes positive emotions as short reactions to certain happenings that are personally meaningful. It is therefore the ability to feel happy at that very moment and to enjoy the present experience. Strümpfer (2004) notes that happiness and feelings of well-being are examples of positive emotions. Those who

experience positive emotions in times of stress are according to Fredrickson (1998, 2001) able to benefit from their broadened thought paradigms. They also regulate negative emotional experiences successfully.

Folkman and Moskowitz (2000) found adaptational significance of positive emotions during the process of coping. Fredrickson, Tugade, Waugh and Larkin (2003) also found that positive emotions can improve the way people cope with their specific losses. People that experience a sense of loss are more able to focus their attention on the tasks that are most important to them and to make progress on these tasks. When these people gain some distance from negative emotions, they can replenish and restore themselves by positive emotions (Fredrickson et al., 2003).

Strümpfer (2004) explains that people who are in leadership positions should understand that the small everyday things under their control seem to have very important facilitating effects. He refers to another facet of Fredrickson's theory, namely that positive emotions serve as operative antidotes for negative emotions's lasting effects. These effects narrow an individual's thought-action inventories.

Isen (2002) states that:

The currently popular foci involving genetic endowment, early childhood experience, or individual differences ... should not obscure the fact that people respond to their surroundings and that a small positive event can have powerful effects on many important processes. Positive emotions are, therefore, not only a source of important strength for people but also constitute one that is potentially available to all of us and those in our charge+(p. 537).

3.8.2.1 Positive emotions stem from positive meaning

Fredrickson (2005) believes that positive emotions stem from the ability to find positive meaning. Individuals find positive meaning in their day to day lives by reconsidering those activities and events that have positive value. When a person is

partaking in a social activity it can, for instance, be interpreted as a feeling of connectedness, belonging and security.

Positive meaning can be derived from challenging physical activities which can be interpreted as personal achievement evoking feelings of joy, love, interest, contentment and other positive emotions. Fredrickson (2005) also refers to other researchers such as Affleck and Tennen (1996); Folkman, Chesney, Collette, Boccellari and Cooke (1996) that discovered the significant therapeutic effects of finding positive meaning.

3.8.2.2 *Positive affect and thought processes*

Positive emotions, i.e. happy feelings, have a very important aiding effect on individuals' ability to think and function (Isen, 2004). Examples of the effect of happy feelings are enhanced, sought-after abilities that underlie innovation, creativity and problem solving in general.

Isen (2004) argues that there is a large body of literature that indicates how positive affect enhances generosity, social responsibility and reasonable helpfulness. Empirical work that was done on the impact of positive affect and its relation to thinking and memory was used to reflect an individual's decision about the most appropriate course of action in any given situation.

3.8.2.3 *Problem-focused coping and emotion-focused coping*

Chalk (2007a, 2007b) states that cognitive dysfunction experienced by specifically MS patients, caused less depression if the patient engaged in high levels of problem-focused coping. Pakenham (1999) reported lower levels of distress and depression among MS patients where they exerted problem-focused coping. Lazarus and Folkman (1984) already noted that theorists contrast the positive results of problem-focused coping against the negative effects of emotion-focused coping. An adaptive response to address an adverse situation does indeed often require problem-solving

activities to take control of the threat, but emotion-focused coping or avoidance may help in maintaining emotional balance during crises.

Unlike problem-focused coping, emotion-focused coping may be ineffective in changing a situation which can be improved by action. It comes to its right, however, in situations where the individual does not have any control over the situation (such as coping with chronic illness). Zeidner and Saklofske (1996) state that avoidance coping (mental disengagement, wishful thinking, escapism, effort to deny) often counters effective coping in stead of aiding it. Interestingly enough, research evidence finds that cognitive avoidance seems to be effective with short-term stressors such as pain, noise and certain medical procedures. Research evidence on the adaptiveness of avoidance coping is, therefore, mixed.

3.8.2.4 *Coping as an important variable when dealing with depression*

One of the most researched topics in psychology, is depression. In descriptions of depression, coping is regarded as a very important variable. According to Zeidner and Saklofske (1996) depressed individuals tend to use avoidance and emotional coping responses instead of problem-solving strategies. Problem-focused coping requires the skill of defining problems, a more external focus and access to a menu of appropriate coping strategies to manage emotions and stressors. Several studies suggest that depressed people seem to favour maladaptive coping strategies (Zeidner & Saklofske, 1996).

3.8.2.5 *Coping with loneliness*

Social psychology defines loneliness (rather tediously) as a relational deficit reflecting social and interpersonal relationships that the individual defines as deficient in meeting his or her needs+ (Zeidner & Saklofske, 1996, p. 516). Loneliness is therefore a result of evaluations that a person's social network is quantitatively too small or qualitatively inadequate. It could be specific to deficits in friendship, romantic, family and/or community relationships. It is of concern that loneliness seems to be associated with mental health and physical health problems, ranging from depression to suicide and substance abuse.

Zeidner and Saklofske (1996) state that loneliness of male and female students correlated positively with coping through wishful thinking. It correlated negatively with problem-focused coping. Other research by Rubenstein and Shaver (1980) suggests that lonely people seem to employ a mixture of coping strategies. They found, for instance that lonely adults employed coping strategies such as %spending money+ (a distracting response), %active solitude+ (a creative use of time spent alone), %social contact+(an attempt to deal directly with isolation), %sad passivity+(a maladaptive way that reflects self-pity). Interestingly enough, it was also found that non-lonely as well as lonely adolescents seem to use sad passivity as a temporary coping strategy in their preparation for initiating active coping methods.

It, therefore, seems that passivity can be adaptive by giving people some quiet time to stabilise themselves before they initiate active coping strategies such as inviting people for a party. This coping style becomes maladaptive when it becomes the dominant style for managing loneliness.

3.8.2.6 Coping strategies and physical health problems

Coping is an important variable in adjustment and recovery from health problems. It is clear, however that %coping is inherently a dynamic, sequential process; and that emotion- and problem-focused coping modes may, therefore, sometimes overlap and become indistinguishable as people deal with complex situations+ (Zeidner & Saklofske, 1996, p.518). There is evidence for and against the adaptiveness of specific coping strategies in cardiac and hypertensive patients. It was found that distraction may have an influence on the recognition and response to unusual symptoms of cardiovascular dysfunction. Then again, active coping seemed to be a contributing facet in the onset of hypertension (Zeidner & Saklofske, 1996).

Research done on cancer patients suggests that multiple coping strategies are required to deal effectively with the multitude of stressors associated with this disease (Zeidner & Saklofske, 1996). Coping with health problems suggests a range of adaptive coping behaviours such as hardiness and acceptance of the illness.

Maladaptive coping behaviours include avoidance, distraction and emotion-focused coping.

3.8.2.7 Post-traumatic stress disorder

Post-traumatic stress disorder (PTSD) was positively related to emotion-focused coping in research findings (Zeidner & Saklofske, 1996). Emotion-focused coping seems to be an effective coping strategy in situations where people have no objective control such as during disaster, combat and crime situations. This coping strategy is less adaptive in post-traumatic situations.

Adaptive responses in adverse situations, therefore, require problem-solving actions to manage a threat. Problem-focused coping is typically efficient in situations where action can change the situation. Emotion-focused coping is helpful in situations where individuals do not have any control over the circumstances (such as coping with chronic illness).

3.8.3 Search for meaning

But there was no need to be ashamed of tears, for tears bore witness that a man had the greatest of courage, the courage to suffer+(Frankl, 1963, p. 114).

In September of 1942, Viktor Frankl, his new wife, his mother, brother and father were under arrest in Vienna and taken to a concentration camp in Bohemia. Events that happened there and at three other concentration camps, led this young doctor to realise the importance of the meaningfulness in life.

Later on, Frankl (1997) was the creator of *logotherapy*, which is a form of existential analysis. *Logotherapy* originates from the Greek word *logos* ("meaning"). It is based on the belief that the main motivational force is to find *meaning in life*. The basic three principles of logotherapy are: Life has meaning under all conditions, even during the most horrific ones; secondly, we have freedom to find meaning in what we experience (or at least in the viewpoint we take when we are in situations of

unchangeable suffering) and thirdly, the main motivation for living is our determination to find meaning in life.

Frankl (1986) postulates that the utmost human victory is achieved even in times when we are uncovered to our exposed existence and even when we are confronted with a most horrifying death. Frankl says: " ... everything can be taken from a man but one thing: the last of the human freedoms . to choose one's attitude in any given set of circumstances, to choose one's own way" (1963, p. 104).

The legacy of Viktor Frankl can be assessed in terms of his voice of hope, as well as his gift to positive psychology. Even in the deprivation and hopeless misery of concentration camps, Frankl was able to exercise the most important freedom of all - the freedom to establish one's own thoughts and mental well-being (Frankl, 1963).

Viktor Frankl (1997) delivers pioneering work in the field of search for meaning. According to Frankl the main motivational force in life is to find *meaning in life*. The basic three principles of his logotherapy are: Life has meaning under all conditions, even during the most horrific ones; secondly, people have freedom to find meaning in what they experience (or at least in the viewpoint taken when one is in situations of unchangeable suffering) and thirdly, the main motivation for living is ones determination to find meaning in life.

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Frankl (2000) discusses three broad approaches regarding ways to find meaning in life. The first is through experiential values. The most significant illustration of experiential values is the *love* one feels towards another person. Through love, people can allow beloved people to develop meaning and by doing so, create meaning for ourselves. Frankl (1963) says, "ō love is the ultimate and the highest goal to which man can aspire" (p. 58-59). Love is according to Frankl (1963) the appreciation of the uniqueness of another person as an individual, with an intuitive understanding of their full potential.

A second means of finding meaning is through creative values, by *action* (Frankl, 1985). This is the traditional existential idea of providing oneself with meaning by becoming involved in one's own projects or, better, in the project of one's own life. This includes the creative act of becoming involved in music, art and writing. Frankl (1985) regards creativity and love as a purpose of the spiritual unconscious, that is, according to him, the conscience. He explains that the illogicality of artistic creation is the same kind of intuition that permits people to recognise the good things in life.

The third means of finding meaning is according to Frankl (2000), is *attitudinal values*. Attitudinal values include such qualities as bravery, compassion and sense of humour. However, Frankl's (2000) most renowned example is finding *meaning by way of suffering*. This happens when suffering becomes something more than merely anguish. By way of meaning, suffering can for instance be endured with dignity.

Frankl (1997) notes that seriously ill people are not frequently given the chance to suffer bravely and to keep hold of their full dignity. Fortunately he adds: "Everything can be taken from a man but one thing: the last of the human freedoms – to choose one's attitude in any given set of circumstances, to choose one's own way" (Frankl, 1963, p. 104).

The search for meaning has been an important focus in a number of prominent stress and coping theories (Schwarzer & Knoll, 2004) dealing with chronic illness. Researchers look at different levels of meaning in the coping process. For instance, situational meaning refers to appraisal of stress where it helps to determine the degree of personal significance of the encounter in relation to a person's beliefs, goals or values. Global meaning, on the other hand, is more concerned with an abstract, generalised meaning that is related to people's existential assumptions or assumptive worlds.

Anderson and Anderson (2004) are concerned with the issue of finding meaning in adversity. They visualise meaning as a powerful human strength commonly associated with the minimisation of harm to an individual's physical and psychological health.

Life is characterised by ongoing change. An individual's physical being changes even though that same person's identity remains essentially the same. It could therefore be said that a meaning of life is an imposition of a stable conception onto a changing biological process+(Baumeister & Vohs, 2005, p. 609).

It seems that although life is characterised by constant change, all living beings strive for stability. An example of human beings that are exposed to change while retaining stability can be found in long term relationships, such as marriages, where ongoing adaptation and mutual evolution coexist with stable meaning. A wedding establishes various lasting meanings and these meanings provide a stable framework for two people who are connected to each other. There are multiple levels involved with the aspect of meaning. People's experiences and behaviours change when they alternate between different levels of meaning.

3.8.3.1 Four needs for meaning

Baumeister and Vohs (2005) state that a quest for a meaningful life seems to be understood in terms of four main needs:

- **The first need**, they propose, is a need for **purpose**. It seems that present events become meaningful because of their connections with future events. These future events provide direction to the present. The present can therefore be steered towards future purposes. There are two main types of purposes. Goals are the first type. The other form is fulfilments that are subjective rather than objective. An orientation towards some or other anticipated future fulfilment, e.g. being in love, going to heaven or living happily ever after is a way of life for someone living with purpose (Baumeister & Vohs, 2005).

- **Values** are a **second need** that seems to provide a sense of goodness to life. Values justify courses of action. Values make it possible for individuals to decide whether certain acts are wrong or right. Values ensure that people remain secure in their belief that they have acted correctly. This phenomenon minimises anxiety, guilt, regret and other forms of distress. Baumeister and Vohs (2005) recall that Victor Frankl emphasised values as the most important form of meaning in life. It is interesting to note that values are hierarchical. Whether something is good or bad is determined by a higher level principle about what is good. Baumeister and Vohs (2005) explain that there are top levels of self-evident good which require no further justification. These are called value bases (Baumeister, 1991). Religious people, for instance, believe that God's will is a value base that is supremely good and right.
- The **third need** in order to have a meaningful life is the need for a **sense of efficacy**. A life with values and purposes, but with no efficacy, is a tragic life. This means that an individual might be able to know what is desirable but, at the same time, is not able to do anything about it. A serious personal crisis originates when an individual lacks the control over the environment that he or she seeks to have. This has a negative impact on his or her mental and physical health (Baumeister, 1998).
- The last and **fourth need** is the need for a **basis of self-worth**. Individuals are constantly looking for reasons to believe that they are worthy and good people. It seems that self-worth can be obtained individually, such as viewing oneself as better than other people (Baumeister & Vohs, 2005). It can also be obtained collectively, such as belonging to a certain group of people that are seen as worthy (Turner, 1975). It is empirically seen that individuals' lives become meaningful because of multiple sources, e.g. work, religion, family, love and various other personal objects.

The meaning of life does not originate in singular aspects. Multiple sources of meaning in life protect people against feelings of meaninglessness (Baumeister & Vohs, 2005). A person can have love, religion or work to give him or her meaning in life when his or her health is affected. To have multiple sources of meaning are beneficial because there is less pressure on each of the individual's resources to satisfy all four needs of meaning.

3.8.3.2 *Suffering and happiness*

Baumeister (1991) discussed extensive research that was done on parenthood and happiness. It was found that having children reduces the life satisfaction and happiness of some parents, but the loss of happiness seems to be compensated for by an increase in meaningfulness. A revolutionary fighter or a terrorist can have a very meaningful life which is very unlikely to be a happy one (Baumeister & Vohs, 2005). It can, however, not be concluded that happiness and meaningfulness are mutually exclusive, nor that they are in partnership. In practice meaningful lives tend to be happier, though. According to Baumeister and Vohs (2005), a way to tie meaning and happiness is to propose that meaningfulness is necessary, but not sufficient, for happiness.

3.8.3.3 *Suffering stimulates the need for meaning*

It appears that suffering stimulates the need for meaning. People often cope with suffering by finding some form of meaning in it. A certain form of control is found when meaning is given to suffering or negative life events. Hilbert (1984) found that people who suffer from chronic pain felt better after they could explain and define the pain, even if nothing physical had been done to alleviate the pain.

Snyder and Pulvers (2001) propose that simply having a definition or label provides comfort and eases stress. Baumeister and Vohs (2005) refer to Taylor's work where she explained that people cope with misfortune and suffering by using three general strategies, namely finding purpose in it, rebuilding a sense of mastery or control and bolstering self-worth (p. 612).

Three of the four needs of meaning correspond with Taylor's idea (efficacy, self-worth and purpose). It could be argued that the fourth need, namely value, deserves a place here too, because people can bear their suffering more easily when they believe their suffering has some positive value (Baumeister & Vohs, 2005).

3.8.3.4 *The process of making meaning*

According to Baumeister and Vohs (2005), meaning-making refers to an active process through which people reappraise and revise a specific event or a series of events in order to find some positive meaning. This concept links with the process from adversity to prosperity that will be discussed later in this chapter under benefit-finding.

The second aspect of meaning-making involves looking for acknowledgement in the effort to understand the event. This is the sense-making function of meaning-making. Park and Folkman (1997) defined meaning-making as a search for significance. Baumeister and Vohs (2005) emphasise that it is tempting to imagine that all the facets of human life evolved because of the fact that they serve a purpose and that it is a part of the grand evolutionary plan, but that neuroscientists state that not all human behavioural and psychological outcome are purposeful from the evolutionary perspective.

Meaningful interpretation and the seemingly universal development thereof suggest that all human beings are inclined to seek meaning. This is illustrated by the eagerness of small children to learn new languages (Kagan, Moore, & Bredekamp 1995). Human beings want to learn and use meaningful thought.

It has been found by several researchers that talking and especially writing about events force a structure onto feelings and thoughts that had not previously been clear. Coping strategies and insights are developed through language. According to Baumeister and Vohs (2005), the background of a story as well as the ordering of events becomes important when telling a story. One's life story includes the context in which events happened, the objective facts and a subjective interpretation.

Finding meaning in adversity is a powerful way of coping, both for enhancing the good and for remedying the bad. The need to reduce suffering urges sufferers and victims to find meaning most urgently. A meaningful life is, according to Baumeister and Vohs (2005), in itself a very positive outcome even if there is no trauma, pathology, misfortune or suffering.

3.8.3.5 *Benefits of meaning-making*

Research offers abundant evidence of the positive effects of meaning-making. Meaning-making allows people to establish their self-worth and identity. There are also psychological and physical health benefits to obtaining meaning in life. Meaning-making research confirms that people who get the most benefits are those people who can change their perceptions of unfortunate circumstances to fortunate ones. Generative people can transform bad circumstances into positive outcomes.

According to Baumeister and Vohs (2005), researchers who examine meaning-making in relation to the physical health and mental health effects, found that meaning-making was associated with positive health outcomes. It was found, for instance, that people who write about their traumatic events found meaning in their suffering because people want to communicate their problems. People who inhibit their impulses and do not communicate about their problems experience some kind of harm to their bodies (Esterling, LaBate, Murray & Pennebaker, 1999).

Baumeister and Vohs (2005) refer to research that was done among HIV positive men who experienced the loss of a lover or close friend to AIDS. It was found that between two and three years after the death of a significant other, the bereaved people who could find meaning in their loss, did not have negative bodily changes such as a rapid decline in their T lymphocyte cells. The same applies to mental health and the positive effect of meaning-making thereon. If people engage in meaning-making, they show better adjustment while dealing with the loss of a family member. Psychological adjustment is predicted when two aspects of meaning-making, namely finding something positive in the experience and making sense of the loss, are present.

3.8.4 Benefit-finding

"Adversity can lose some of its harshness through ... finding the good in bad events" . Affleck and Tennen (1996).

Over the past ten years researchers have redirect their attention from the negative impact of traumatic events towards the positive. An expanding body of literature relate how patients with serious illnesses have changed their lives in positive ways as a result of traumatic events (Helgeson, Reynolds & Tomich, 2006). These positive changes have been termed *stress-related growth*, *post-traumatic growth* or *benefit-finding* (Helgeson et al., 2006). Cognitive adaptations can help patients to restore comforting views of themselves, other people and the world (Affleck & Tennen, 1996, p. 900).

Bower, Low, Moskowitz, Sepah and Epel (2008) investigated literature and research outcomes on the concept of benefit finding. They posit that the majority of research on benefit-finding found evidence that benefit-finding seems to be linked to positive variations in physical health. They propose that benefit-finding plays a stress buffering role. They designed a model that focuses on psychological processes that seem to influence physical health. A number of studies examined the effect of benefit-finding on physiological reactivity. Socially related benefit-finding was the main focus. Compelling evidence shows that social support buffers physical stress responses.

Pakenham (2007) states that benefit-finding could be defined as the identification of benefits during adversity. He proposes that successful adaptation in the midst of adversity is about finding benefit in suffering. Benefit-finding is the form of cognitive adaptation where individuals evaluate circumstances in a positive way. This brings about a sense of mastery that preserves self-esteem and assists people to process negative events mentally (Danoff-Burg & Revenson, 2005).

Park and Folkman (1997) define benefit-finding as a cognitive reappraisal coping strategy that belongs to the meaning-based category of coping processes. Pakenham and Cox (2009) posit that benefit-finding is a predictor of recent and future adjustment in patients suffering from chronic or life-threatening diseases. Benefit-finding is also defined as %identification of benefit from adversity+ (Danoff-Burg & Revenson, 2005, p. 91).

3.8.4.1 *Response to illness – benefit-finding experiences*

Research suggests that a response to benefit-finding in illness often occurs as a component of positive psychological responses (Danoff-Burg & Revenson, 2005). It is evident from numerous studies that some people who are physically ill display high levels of positive affect and also find personal growth as an outcome of their illness experience. Danoff-Burg and Revenson (2005) further found that patients who have had heart attacks reported building valuable self-knowledge and a positive change in their priorities and values. From adverse situations people can derive find benefits such as an enhanced sense of spirituality, deepened interpersonal relationships and overall heightened appreciation for life in general.

3.8.4.2 *Benefit-finding and sense-making*

Research by Davis, Nolen-Hoeksema and Larson (1998) found that two constructs for meaning, namely benefit-finding and sense-making, helped the relatives of terminally ill patients to make sense and to find benefit from their experience. The emphasis is ultimately on the adaptational value of finding meaning in a stressful situation or incident.

Davis et al. (1998) state that sense-making is more about finding an explanation for what happened, where one has to adjust one's existing schemata or where one has to integrate the experience into one's own framework. Factors such as religion, knowledge about health, antecedents or consequences of a disease are important when one refers to one's existing schemata. On the other hand, the authors explain

that benefit-finding is more about finding meaning by considering all the positive implications of a bad event.

3.8.4.3 *To find benefit in adversity*

Some people who are seriously ill are able to find benefit in their adversity which includes positive alterations in their personal relationships (Dunoff-Burg & Revenson, 2005). Numerous studies found that benefit-finding was related to the coping strategies of seeking support and positive reappraisal of the illness. In some areas it was only related to reduce emotional distress (i.e. anxiety and anger, but not depression).

Breast cancer patients experience was an increase in personal growth, particularly with regard to relationships, appreciation of life and spirituality. Dunoff-Burg and Revenson (2005) provided numerous examples of benefit-finding as specifically a cognitive reappraisal process. An example is where some patients had conflicting feelings when accepting assistance with physically demanding tasks, but still accepted the help from others because for them it was a sign of personal growth.

Ackroyd, Fortune, Price, Howell, Sharrack and Isaac (2011) conducted the first study to examine factors that might predict adversarial growth in people with multiple sclerosis and their life partners. Ackroyd et al. (2011) state that previous researchers reported the deepening of relationships, increase of spiritual interests and enhanced appreciation of life as benefit-finding factors that were related to positive coping strategies.

Ackroyd et al. (2011) note that patients' perceptions of their illness play a crucial role in their adjustment process. Patients' perceptions of their illnesses are said to be parallel to perceived emotion-focused coping as well as stress. It was found that dissimilar perceptions of an illness held by patients and their partners brought about increased psychological distress, especially for the partners.

Since Ackroyd et al. (2011) were the first researchers to examine factors that might predict adversarial growth in people with MS and their partners; it is interesting to note that adversarial growth was not associated with demographic variables. It was also not associated with illness-related variables such as MS severity or the type of MS that the patients have. The researchers also found no significant relationship between the duration of the illness and the growth of illness. The only significant predictor of the partners' growth was the patients' adversarial growth. The idea of a "communal search for meaning" (p. 377) was the partners' as well as the patients' experience of the trauma of having a chronic illness. Subsequently, they found positive factors of the illness together.

3.8.4.4 Women and younger individuals engage more in benefit-finding

Helgeson et al. (2006) found that women and younger individuals engaged more in benefit-finding than men and old aged individuals. Professor Helgeson has studied the adjustment to chronic illness for many years (from 1993 to 2007) and her research has included patients with Type 1 diabetes, prostate cancer, breast cancer, juvenile rheumatoid arthritis and heart disease. The gender difference, where women and younger individuals engaged more in benefit-finding than men and older individuals, is consistent with other research on coping that showed that women engage more positively in self-talk than men do. Objective severity and subjective perceptions of stress related positively to more benefit-finding. The severity of the threat seems to motivate benefit-finding.

According to Helgeson et al. (2006) it makes perfect sense that more severe trauma is needed before people consider making serious changes in their lives. Regarding personality variables it is not surprising that optimists easily derive benefits from trauma (Helgeson et al., 2006). Religiosity was also related to benefit-finding. This seems to reflect the idea that spiritual growth is one of many divisions of benefit-finding. Helgeson et al. (2006) also found that benefit-finding was related to coping strategies.

According to Helgeson et al. (2006), it seems simple to merely ask individuals whether they have experienced something positive from their traumatic event. They

emphasise, however that the thought processes underlying individuals' responses are much more complicated than what meets the eye.

The literature frequently debates whether different types of growth are conducive to better physical and psychological health. One expects growth to be related to positive health outcomes as far as it concerns individuals making huge changes in their lives as a result of traumatic events. It has also been proposed that benefit-finding is really coping strategies that are utilised to control suffering (Helgeson et al., 2006).

Benefit-finding may be an outcome of interest in its own right as well as an outcome that indicates the positive outcomes from trauma rather than the mere lack of distress (Helgeson et al., 2006). Simultaneously, however, benefit-finding was associated with intrusive and avoidant thoughts about a patient's illness. This might seem to show an inconsistency with the findings mentioned above. In fact, because benefit-finding is related less to depression and more to intrusive thoughts (such as thoughts about posttraumatic experiences), it might explain why studies have been inconsistent on the subject of the relation between benefit-finding and mental health.

Helgeson et al. (2006) also found that instead of referring to these constructs as markers of mental health, many investigators prefer to use these constructs for reflecting cognitive processing as well as to understand traumatic events. When a person experiences intrusive thoughts about a stressor, it might be a signal that he or she is working through the stressor's implications and such processing might result in growth. Some even argue that contemplation and consideration of the stressor is required in order to achieve growth. The relationship between benefit-finding and thoughts makes more sense if intrusive and avoidant thoughts are makers of cognitive processes rather than of distress. Therefore, such markers are not inconsistent with the findings related to benefit-finding, depression and positive affect.

The only physical health outcome used in the study of Helgeson et al. (2006) was people's subjective reports of their physical well-being, for instance physical limitations experienced in daily activities. It was found that benefit-finding is unrelated to measures of anxiety, global distress and quality of life. Pakenham and Cox (2009) were concerned that the dimensional structure of benefit-finding in chronically ill individuals had not yet been researched adequately. The research done by Pakenham and Cox (2009) supports the view that benefit-finding becomes relevant only later in the adjustment process of multiple sclerosis or is at the least strengthened during the stressful process of dealing with the illness.

According to Bower et al. (2008), there is compelling evidence that benefit-finding seems to boost physical health. Benefit-finding seems to involve changes in various psychological areas, such as relationships, changes in appraisal and coping processes, priorities and positive effect. The outcome promotes restorative processes such as anabolic hormone production and heart rate variability. Bower et al. (2008) found that benefit-finding in stressful experiences seems to show an efficient response to future stressors. Finally, links between benefit-finding and baseline neuroendocrine and immune function give evidence for links between the systems.

Bower et al. (2008) show in their model that emotional, cognitive and motivational constructs fall within the conceptual frame of benefit-finding. Some of these constructs seem to be more relevant to stress physiology than others.

Reconstruction processes, such as benefit-finding, are triggered by an ideal mix of strategies that might include cognitive-behavioural strategies, person-centred strategies and existential strategies (Pakenham & Cox, 2009). Bower et al. (2008) propose a construct that is related to benefit-finding, namely *rapid habituation to repeated stress*. According to these authors, normal habituation is defined as a gradual decrease in response magnitude during repeated or prolonged presentations of a stressor+ (p. 232). Lack of habituation is related to physical factors such as exhaustion. Lack of habituation to repeated stressors is characterised by repeated hits of stress, but with no eventual habituation. On the other hand, rapid habituation

is characterised by an initial response to a new factor with habituation that takes place when the new factor is exposed for the second or the third time. Bower et al. (2008) suggest that benefit-finding seems to enhance efficient physical habituation to repeated stressors.

3.8.5 Hope

Hope is the physician of each misery.+. Irish Proverb.

Hope is defined as the belief that one can find pathways to desired goals and become motivated to use those pathways+(Snyder, Rand & Sigmon, 2002, p. 257). Erikson (1964) said, Hope is both the earliest and the most indispensable virtue inherent in the state of being alive ÷ if life is to be sustained hope must remain, even where confidence is wounded, trust impaired+(p. 115).

The concept of hope can be traced to the works of Marcel (1962), Stotland (1969), Lynch (1965) and Menninger (1959). These authors attempted to articulate the essence of hope, a difficult endeavour in light of the abstract and elusive nature of the concept. Fromm (1973) identified the difficulty inherent in defining and describing hope. Words, because they are imprecise, often obscure the meaning of hope. In addition, since definitions are attempts to accurately describe phenomena, defining an abstract concept such as hope is doubly difficult. As a result of this lack of conceptual clarity, a knowledge gap in acquiring agreement on an acceptable definition of hope exists. One is left with an intuitive personal perception of hope that is difficult to articulate to health professionals, let alone the general population. Despite this difficulty in articulating the essence of hope, many differing definitions of hope exist.

Historically, hope has been thought to be a crucial element for coping with illness. Menninger (1959) addressed the annual meeting of the American Psychiatric Association, describing hope as a vital component in our everyday life. He was surprised that hope, a crucial element, had received such sparse attention in the literature. While the literature provided anecdotal descriptions of hope there is an

obvious scarcity of research studies which have investigated hope (Dubree & Vogepohl, 1980; Sotland, 1969).

Thirty years later, there continued to be limited empirical descriptions of hope (Herth, 1989; Hinds, 1984; Miller, 1985; Nowotny, 1989; Owen, 1989). It is such an intangible concept that researchers have shied away from investigating its dimensions. Earlier quantitative research did not lend itself to measurement of an evasive concept such as hope. In recent years, the growth of qualitative research and improvements in the development of quantitative measuring tools has provided the necessary medium for researching more abstracts concepts.

Most theories and ideas regarding the concept of hope can be grouped into one of the following categories: emotion-based or cognition-based. These two perspectives are beginning to merge to some degree, imbuing hope with both affective and cognitive qualities. For the purposes of this part of the chapter, these two categories will be discussed separately, though an overlap may be noticed.

Averill, Catlin and Chon (1990) described hope as an emotion. They argue that this emotion is governed by cognitions. According to them, environment is highlighted as having an effect on the deterioration or development of hope. They explain that hope is most appropriate when goals are (a) under control, (b) reasonably attainable, (c) acceptable at a moral and social level and (d) viewed as important by an individual. According to Averill et al. (1990) hope can only be understood within a cultural and social context.

Mowrer (1960) views hope on a more behavioural level with an affective-form as a secondary reinforcement. Mowrer (1960) used animals in his research. When he worked in a stimulus-response paradigm, the emotional component of hope appeared when a stimulus associated with pleasure occurred. When an affective ingredient was introduced, the animals anticipated the outcome as pleasurable. By contributing to the reinforcement of the original stimulus, hope sustained a desired behaviour. The emotion of hope is seen to propel animals towards their goal.

Marcel (as cited in Godfrey, 1987) advanced, in contrast to Mowrer's stimulus-response paradigm, to a more philosophical approach. He suggested that hope was illustrated in the idea, "hope in thee for us" (Godfrey, 1987, p.103). This view looks at hope as it applies to society rather than the individual. Marcel (as cited in Godfrey, 1987) worked with prisoners of World War II. Based on his work with these prisoners he explained that hope was an affective form of coping. This form of coping could be used in the worst circumstances of imprisonment. It seems that Marcel's view defines hope as being valid only in helpless situations.

3.8.5.1 *The cognitive side of hope*

In popular literature and prose, hope is often treated solely as an emotion, a particular feeling that allows one to sustain belief in dire circumstances. The cognitive side of hope, however, receives more research attention (Lopez et al., 2004). The work of Erikson (1964) for example, suggests hope as "the enduring belief in the attainability of fervent wishes, in spite of the dark urges and rages which mark the beginning of existence" (p.118). Hope is, therefore, a thought or belief that allows individuals to sustain movement towards goals. Erikson places hope in a developmental context, positing that we hope from birth; moreover, he discusses the conflicts that arise internally because of hope. "our fervent wishes" may come into conflict with those of others, especially when we are infants.

Individuals are therefore allowed to sustain movement towards goals via hope as a belief or thought.

Lopez et al. (2004) refer to Breznitz (1986) where he suggests that hope is about a brief thought or a description of a cognitive state. Breznitz (1986) takes a cognitive view when defining hope. He explains that hope must be of sufficiently strong and persistent nature to bring about a physiological response. Only then, can hope have an influence on an individual. A mere thought for example, "will be fine" has a smaller reaction than what the actual hoping has on the body. To truly experience the essence of hope, Breznitz distinguishes between the work of hoping and hope.

The work of hoping is an active process in which one must engage in order to truly experience the core of hope.

Other theorists, like Godfrey, Gottschalk and Stotland emphasise the relationship between expectancy and perspective and hoping (Lopez et al., 2004).

3.8.5.2 *Perspective and expectancy are involved in hope*

Godfrey (1987), Gottschalk (1974) and Stotland (1969) emphasised that perspective and expectancy are involved in hoping. Stotland (1969) conceptualised hope as *an expectation greater than zero of achieving a goal* (p. 2). Borrowing from their background in social psychological theory and cognitive schemas, Stotland (1969) added that the degree of hope was to be determined by the perceived probability of achieving the goal and the importance of the goal itself. If a sufficient level of significance is attached to the particular goal, then hope is *ignited*, mediating between the desire and the actual movement towards the goal.

3.8.5.3 *Hope – the perceived probability of achieving a goal*

Stotland (1969) conceptualised hope as an expectation of goal achievement; setting the foundation for many future works on hope. Obayuwana and Carter (1982) built on this conceptualisation by comprising a definition of hope from 500 participants' descriptions of hope. The components of the definition include a state of mind that resulted from ego strength, positive outcome, religion, family, education and economic assets. Miller and Powers (1988) defined hope as *an anticipation of a future which is good*; based on mutuality (relationships with others), a sense of personal competence, coping ability, psychological well-being, purpose and meaning in life and a sense of *the possible*.

To achieve hope, a person must invest energy to become actively involved in the process of hoping (Beuhler, 1975; Dufault & Martochio, 1985; Fromm, 1973; Hinds, 1984; McGee, 1984; Stanley, 1978). Other researchers suggest individuals must also incorporate hope into their own belief system to initiate action sufficiently (Frankl, 1964; Fromm, 1973; Hickey, 1986; Lynch, 1965; Raleigh, 1980). One would

agree with Hinds (1984) that early views, conceptualised hope as merely wishing that something would happen. In more recent work, hope is conceptualised as more than simply wishing. Hope encompasses positive expectations of the future which acknowledges realities of the present situation (McGee, 1984).

Stoner and Keampfer (1985) found that hope is based on the person's perceptions of life expectancy, which affect their ability to set and attain goals. These perceptions are individually defined and may not be congruent with the perception of hope by professionals. Hope may, therefore, be significantly different from the viewpoints of individuals and health care professionals respectively.

A belief in hope as a multi-dimensional construct is postulated to be a crucial element in health and illness because it may affect people's psychological well-being and coping abilities (Dufault & Martochio, 1985; Jalowiec & Powers, 1981). Herth (1989) defined the multi-dimensional components of hope as "an energised state characterised by an action-oriented, positive expectation that goals and/or needs for self and future are obtainable and that the present state or situation is temporary" (p. 69).

In summary, hope has been described by theologians, philosophers and researchers. Some researchers have recognised the multi-dimensional definition described by Dufault and Martochio (1985). According to Foote, Piazza, Holcombe, Paul and Daffin (1990), hope is an essentially positive occurrence necessary for healthy coping. Korner (1970) and Weisman (1979) postulated that hope plays an important role in the coping process, while Owen (1989) suggested that hope may be a criterion for coping with loss.

An individual's perceptions of his or her capacity to clearly conceptualise goals, to develop the specific strategies to reach those goals (pathways thinking) and to initiate and sustain the required motivational strategies (agency thinking) are reflected by the person's hope, as explained by Joseph and Linley (2004) in the hope theory. Successful goal pursuit is achieved and maintained by both the

pathways and agency components and neither these components can achieve sustained goal pursuit on their own. Interrelatedness between these components can be described as additive, reciprocal and positively related, but not as synonymous (Lopez et al., 2004).

Joseph and Linley (2004) explain that in the context of the hope theory, a goal is anything that an individual desires to experience, create, get, do, or become and it can therefore be a significant, life-long pursuit, or a mundane and brief desire. Goals can also differ in their probabilities of attainment that vary from very low to very high. High-hope individuals prefer the type of goals known as *stretch goals*, which are slightly more difficult to obtain than previously attained goals.

A goal itself, future-orientated agency and pathways-related processes are given different emphases in positive psychology concepts such as goal theory (Covington, 2000; Dweck, 1999), optimism (Scheier & Carver, 1985), self-efficacy (Bandura, 1982) and problem-solving (Heppner & Peterson, 1982). The hope theory equally emphasises all of these goal-pursuit components (Snyder, 1994).

3.8.5.4 Hope theory

3.8.5.4a Goals

Snyder, Rand and Sigmon (2002) describe human actions as goal-directed. Goals are then the targets of mental action sequences and they provide the cognitive component that anchors the hope theory+ (p. 258). They explain that goals are short-term or long-term and that they need to consist of enough value to occupy the conscious thought. It is important to note that goals are perceived as attainable but that there is also a degree of uncertainty around goals.

3.8.5.4b Pathways thinking

In order to reach their goals, people must view themselves as being capable of generating workable avenues to reach their goals. The *pathways thinking* process signifies an individual's capability of generating workable routes to desired goals (Snyder, Lapointe, Crowson & Early, 1998).

Pathways thinking involves thoughts of being able to generate at least one and often more, usable routes to achieve a desired goal, no matter the situation. Producing several pathways are important when an individual encounters impediments. High-hope persons perceive that they are facile at finding alternate routes in challenging situations. Moreover, high-hope people actually are effective at producing alternative routes when impediments are encountered in their current chosen pathway (Irving, Snyder & Crowson, 1998; Snyder et al., 1991).

3.8.5.4c *Adding pathways and agentic thinking*

Agency, the perceived capacity to use one's pathways to reach one's desired goals, forms the motivational component of the hope theory. If the word *agency* is used in this sense, *agentic thinking* entails starting to move on a certain pathway to one's goals as well as persisting on that pathway. High-hope people often engage in agentic self-talk such as "I can do this" and "I am not going to be stopped". Agentic thinking may relate to any goal-directed thought, but agentic thinking is especially important in situations where people face impediments. Situations that encompass blockage encourage the person in such situations to use agency in order to find the best alternative pathway to reach his or her goals (Lopez et al., 2004).

Lopez et al. (2004) explain that one must note that hopeful thinking requires both the capacity to think up workable paths as well as goal-directed energy to see them through. It can be said that successful pathways and successful agency interact to achieve a positive motivational state.

Snyder (1994) argues that the essence of hope theory is the belief and ability to accomplish what we desire. He proposes that hope is created as we successfully create workable strategies to achieve certain goals and possess positive beliefs about the ability to plan, commence and uphold goal oriented behaviours. Lopez, Floyd, Ulven and Snyder (2000) state that hope is cultivated by focusing on future-oriented goal striving rather than attempting to alter attributions related to negative events.

Lopez et al. (2004) propose that this perspective of hope allows the conclusion that hope is malleable and that it can be the spark for any pathway to change. Beneficial change often results in more hope to create a good life. Most people have the capability to hope. This capability accentuates the change agent of hope, which requires ample naming and nurturing as a personal strength in the context of supportive helping relationships. Hope finding, bonding, enhancing and reminding are the essential strategies for accentuating hope. *Hope-enhancing* strategies typically involve requiring clients to conceptualise reasonable goals more clearly; produce numerous pathways to attainment; demand the energy to maintain pursuit and view insurmountable obstacles as challenges to be overcome.

Hope can exist as either a relatively stable personality disposition or as a more temporary frame of mind. In the same breath, hopeful thought can occur at various levels of abstraction. For example, individuals can be hopeful about achieving goals in general; goals in a certain life arena or one goal in particular. Preparing a person for therapeutic change requires building personal resources. Formal and informal means are used to find the type of hope most relevant to each person's specific goal pursuit (Lopez, et al., 2004).

3.8.5.4d *Victor Frankl and hope*

As a prisoner of war, Victor Frankl was intrigued by the number of prisoners who were able to hold onto hope for a good future and to endure the atrocities inflicted on them. He reported observing men who lost their ability to hope and subsequently died, while those who were able to persevere and hope, survived (Frankl, 1964). Stotland (1969) concurs that hope is the motivating force for coping resources.

The significance of hope for survival is further supported by physicians' reports of survivors of concentration and prisoner of war camps who exhibited psychological changes that pre-empted their death (Dubree & Vogelpohl, 1980; Korner, 1970). This positive relationship between hope and survival has also been found in studies of burnt children and their hopeful parents, of women with breast cancer, of patients who had coronary bypass surgery and of survivors of natural disasters and concentration camps (Miller, 1985).

3.8.5.4e *Religious affiliation and hope*

Many anecdotal reports suggest religious affiliation is a strong player in maintaining hope (Lamb, 1988; Lynch, 1965; Marcel, 1962). Herth (1989) found in a correlation study regarding levels of hope and levels of coping response that participants with a strong religious faith had significantly higher mean scores on the Herth Hope Scale and the Jaloweic Coping Scale. It would seem that having something to believe in, as opposed to merely following religious practices, is a key ingredient to inspiring hope.

Hope is thought to influence an individual's ability to cope with medical illness, the resolution of social and psychological dilemmas and anticipated stressors (Gottschalk, 1974).

3.8.5.4f *Hope and coping*

The interrelationship between hope and coping as set out in the literature is confirmed by the findings in research (Herth, 1989, 1990; Hinds & Martin, 1988; Lazarus & Folkman, 1984; Weisman, 1979). This interrelationship depicted that where a high level of hope was found, so too could a high level of coping be found and vice versa.

According to Murnaghan (1992), key components such as hope, leads to coping strategies that are used for dealing with stressful situations. It is suggested that patients in hospital, with a lack of support and a sense of powerlessness, have lower levels of hope (Greene, O'Mahoney & Rungasamy, 1982).

Murnaghan (1992) found a significant positive correlation between hope and other key components of coping, namely optimistic and supportant components. McGee (1984) makes it clear that the supportant component was related to hope in that a sense of mutuality was present when the patient had family, friends, professionals and a belief in something or someone. Miller (1989) and Murnaghan (1992) found that sources of hope include family, significant others and religion.

The optimistic component of hope sheds light on the importance of having a positive attitude when coping or attempting to cope (Murnaghan, 1992). Some patients can

be described as %realistic copers+, where hope predominates even when the patient, in fact, acknowledges the realities of his or her situation (McGee 1984). Strategies used to obtain a positive attitude include %having a sense of humour+, %telling self not to worry+, %try to think positively+ and %think about the good things in life+(Murnaghan, 1992). This was confirmed by observations of expert nurses (Owen, 1989). Murnaghan (1992) found effective %copers+ to be patients who remained optimistic despite their challenging situation. A patient, for example, stated that she wanted to live her life to the fullest even though many of her hospital visitors brought gloomy attitudes along on their visits.

Worthen and Isakson (2010) explain that there are multiple mechanisms that influence the ability to develop hope. Examples of such mechanisms are, amongst others, reward and incentive systems, self-regulation abilities, attachment and bonding activities, memory retrieval and suppression, anticipatory abilities, attention regulation and a decision making ability.

Joseph and Linley (2004) discuss the link between the ability to clearly conceptualise goals and hope.

3.8.5.4g *Benefits of optimism and hope*

Worthen and Isakson (2010) argue that there are physical, mental health and spiritual advantages to more hopeful orientations. Hope helps to cope with adversity and hope also aids people to improve their general life satisfaction. According to Peterson (2006) hopeful people make better lifestyle choices in areas such as eating, drinking and exercise. They recover more effectively from illness and injury (Snyder et al., 2005) and they have better life expectancies (Malinchoc, Colligan, Maruta & Offord, 2000).

Hopeful people manifest less anxiety and depression and experience increased life satisfaction, positive mental health as well as personal adjustment (Worthen & Isakson, 2010). Gottschalk (1985) states that people with elevated hope levels progress the most with counselling and they also persist in times of adversity (Scheier & Carver, 1992). Affleck and Tennen (1996) found that hopeful people are successful in finding benefit from painful experiences and Sympson (2000) reports

that individuals with high hope experience less feelings of loneliness. Hopeful students experience improved academic success (Snyder et al., 2005) and optimistic individuals enter settings in which good things can and do happen more readily (Peterson & Steen, 2005).

3.8.5.4h Conclusion to hope theory

Hope is accentuated with strategies incorporated into a clinical approach called *hope theory* (Lopez, Floyd, Ulven & Snyder, 2000). Clinicians called for a systematic application of the principles of hope theory in a therapeutic context Hope theory was developed in response to the patients' needs. Dozens of strategies for accentuating hope crystallised over fifteen years of the scientific examination of hope theory following its inception. Application of these strategies is steadily taking flight, but many clinical needs are yet to be addressed. Further development is required.

3.8.6 Sense of humour

"Why did the pope cross the road?" "The pope crosses everything." . Anonymous

Adamle and Turkoski (2006) quote Henry David Thoreau just hours before his death when his Aunt Louisa asked him if he had made peace with God. He protested: "I never knew we had quarrelled!" Peterson and Seligman (2004) describe humour as the playful enjoyment, recognition and creation of (a) incongruity; (b) the ability to make others laugh or smile; and (c) a cheerful way to sustain a good mood by composing a view on hardship that allows one to see its lighter side.

3.8.6.1 The term "humour"

Peterson and Seligman (2004) explain that the term *humour* could be used for all funny things, including the capacities to enjoy, create, interpret, perceive and relay incongruous communications. Because humour has such positive connotations, the darker side of humour such as sarcasm or ridicule is often neglected. Contemporary research hypotheses seldom consider that humour might have a down side.

Erickson and Feldstein (2007) conceptualise humour as a multi-faceted construct involving emotional, social, psycho-physiological, behavioural and cognitive components. They describe affiliative humour as 'the tendency to joke around others, tell amusing stories and laugh with others ... to enhance relationship' (p. 256). It seems that this form of humour is associated with high self-esteem, psychological well-being and cheerfulness. It is negatively correlated with anxiety and depression.

Interestingly enough, Erickson and Feldstein (2007) note that research has found that 'boys used aggressive and sexually-related strategies more, whereas girls reported that humour had a greater ability to cheer them up' (p. 258). Humour can be conceptualised as a defence mechanism (Erickson & Feldstein, 2007). Challenging or threatening situations can be faced by using humour without being overwhelmed by possible negative emotions. These defences can be classified into two categories, immature and mature. Immature defences include distorting conflict and denial. Mature defences imply maintaining the ego and reality in the process and synthesising stress. It seems that in a defence paradigm humour is most often viewed as a mature defence.

Over the past decades, the beneficial effects of humour have increasingly become evident (Adamle & Turkoski, 2006). Humour that has been initiated by care-givers as an intervention in healthcare has huge emotional and physiological benefits. Little research has been done though on patient-initiated humour. Patients who use humour to relieve feelings of uncertainty, embarrassment, or feelings of stress are inherently interacting with their care-givers. According to Adamle and Turkoski (2006) patients using humour do so more to lessen feelings of dehumanisation than to make light of the situation that they are in. It seems that humour is therefore an interactive process that includes important aspects of communication.

Adamle and Turkoski (2006) explain that patients observe their care-givers for a response to their sense of humour. Open, accepting responses indicate a form of understanding. Christie and Moore (2005) posit that humour is a vehicle for

expressing emotions rather than being a pure emotion in itself. They posit that humour is being viewed as an applied therapy in health care.

Erdman (1994) notes in her study *Laughter Therapy for Patients with Cancer*, that it is very important to make sure that a sense of humour persists even during the bleakest times for patients, their families and medical staff in hospitals. Laughter defuses tension among people, eases the mind and has a positive physiologic effect on patients. Using humour as a nursing intervention helps to bring an important light hearted facet into difficult scenarios (Erdman, 1994). Humorous novelties such as films and books, help suffering patients to have lighter thoughts.

3.8.6.2 Humour has been shown to relieve stress

Humour has been shown to relieve stress for patients and families. In fact, both directions of humour, i.e. humour initiated by a care-giver as well as humour initiated by the patient can provide an outlet for emotions (Adamle & Turkoski, 2006). It also serves to break down communication barriers. The use of humour is recognised as beneficial to both cognitive and physiological health. It was Freud that defined humour as catharsis *acting on the body and facilitating discharge of negative emotions in the face of hardships of everyday life* (Adamle & Turkoski, 2006, p. 639).

Interestingly enough, humour has been shown by Martin and Dobbin (1988) to expand lung capacity, produce endorphins in the brain, strengthen abdominal muscles and increase immunoglobulin A, one of the major antibodies that is produced by the immune system.

3.8.6.3 Humour improves therapeutic relationships

On the emotional side, humour improves therapeutic relationships, releases hostile feelings, reduces resistance to help and lessens anxiety and embarrassment incurred during times of care (Adamle & Turkoski, 2006). Wanzer, Booth-Butterfield and Booth-Butterfield (2005) state that it is not possible to avoid all aversive situations in life. We live in environments that are filled with distress. It is critical to

be able to use communication to cope with stressors and at the same time remain happy and productive.

These authors explain that effectively communicated humour appears to be a positive way in social and task settings. They add that humour is recognised as a basic coping device for both health care-givers and patients. They describe humour as a versatile communication skill used frequently by both patients and health care providers in a variety of medical contexts+(p. 106).

Wanzer et al. (2005) refer to research of Johnson who examined the types of humour used by patients with breast cancer to cope with their cancer and a how nurses use this humour communication effectively.

3.8.6.4 *Humour relieves the pain in painful situations*

Strümpfer (2004) says: "It is well known that humour, more than anything else in the human make-up, can afford aloofness and an ability to rise above any situation, even if only for a few seconds+(p. 42). Strümpfer (2004) describes a sense of humour as the ability to appreciate and discover comic or amusing situations and then to express it again by repeating them in a way that brings forth mirth, a smile or an unrestrained laugh. According to him, the most important part of humour is that it gives rise to positive emotions, both in the giving and the receiving. Humour also relieves the pain in painful situations associated with disappointments and failure. Humour creates better perspective for people in challenging situations.

Lefcourt (2005) mentions a study examining the responses of patients being hospitalised for orthopaedic procedures. They found that humour was useful in the reduction of pain after orthopaedic surgery. Their findings were that patients exposed to humour-based literature and visuals during their recovery period requested significantly fewer analgesics (aspirin and tranquilisers) than the patients that were not exposed to such humour. An interesting finding was that within the group of patients that requested fewer analgesics, was a subdivision of patients that

were not only exposed to humour but could choose the source of humour. Patients that could choose the source of humour requested even fewer analgesics. Humour may be a positive asset in the recovery from illness and may also help in coping with the debilitating effects of pain and fear that are linked to medical threatening situations.

Cogan, Cogan, Waltz and McCue conducted two experiments by using a blood pressure cuff to induce discomfort (Strümpfer, 2004). In an experiment they proved that listening to a laughter-inducing audio tape raised discomfort thresholds just as much as a relaxing-inducing tape. Both such tapes had a better outcome than a tape depicting a gloomy narrative or no than no tape at all. The authors therefore argued that pain can be reduced by naturally occurring, non-effortful laughter just as effectively as by other behavioural strategies of minimising pain sensitivity, while the latter strategies require training in order to be effective.

3.8.6.5 *The effect of humour on immune system functioning*

Immune system functioning is strongly affected by psychological experience. Immune-suppression that leaves a person more vulnerable to illnesses is a result of stressful situations (Lefcourt, 2005). Humour, which can be regarded as a reflection of a positive emotional state, seems to be an antidote to negative affects that cause immune-suppression. Interestingly enough it was found that laughter significantly increased salivary immunoglobulin A which is regarded as the first line of defence against respiratory illnesses. Lefcourt (2005) also mentions research that Berk and his colleagues undertook. They found that joyful laughter triggered during a humorous film increased spontaneous lymphocyte blastogenesis. Hereby, it seems that positive changes in the immune system are not restricted to levels of immunoglobulin A only.

Humour creates the opportunity to review painful situations as bearable events, as less important and as funny matters. Frankl (1964) wrote that even in dire circumstances like that of a concentration camp, a sense of humour was indeed present. Strümpfer (2004) quotes Frankl's words %humour was another of the soul's

weapons in the fight for self-preservation". Strümpfer (2004) explains that smiling and laughter are expressions of positive emotions. As an individual creates a positive perspective on stressful events, or as the individual understands the distressing situation, stress is reduced. This produces positive emotions of amusement or relief which trigger laughter. Strümpfer (2004) refers to Cousins (1976) who indicated that laughter is an effective weapon against pain.

3.8.6.6 Humour decreases stress hormone levels

Schneider (2009) proposes that although humour can decrease stress, fear and anxiety, it also seems to decrease stress hormone levels but simultaneously increases immune function and improves respiration. She states that it was found that humour relaxes patients, improves clinician-patient communication and increases comfort levels. Schneider (2009) felt relatively little research has been done regarding the use of humour as a coping strategy for individuals with chronic illness. In her study she investigated the use of humour as a coping strategy for care-givers of individuals with Alzheimer's disease.

3.8.7 Resilience

"Resilience lets you bounce back" . Tugade and Fredrickson (2004).

Garmezy (1973) published the first research findings on resilience. He used epidemiology (the study of factors determining which individuals will contract spreading diseases and which will not) as a vantage point to determine the protective factors which enable the alleviation of severe risks. Garmezy and Streitman (1974) then created tools to investigate systems that support development of resilience.

The concept of resilience has been known for centuries and is evident in fairy tales, art, literature and myths (Masten & Reed, 2005). In the nineteenth and early twentieth centuries, when psychology developed as a systematic science, an interest in individual adaptation to the environment started to develop. An example of this

adaptation is the remarkable human capacity to overcome adversity; a capacity that can even be found in some individuals waiting to be executed.

3.8.7.1 Definitions of resilience

Psychological resilience is about an individual's tendency to cope with adversity and stress. It is about utilising the experience of adversity to function better than expected (Masten, 2009).

Neill (2006) posits that psychological resilience refers to an individual's ability to endure stressors such as mental illness or a constant negative mood. This is the typical psychological view of resilience and defined in terms of a person's capacity to avoid psychopathology in spite of complicated circumstances.

Masten and Reed (2005) define resilience as a class of phenomena characterised by patterns of positive adaptation in the context of significant adversity or risk+ (p. 75). Rutter (2007) states that the concept of resilience means that some people have a comparatively good result despite their suffering experiences. This implies relative resistance to bad experiences, or the overcoming of adversity.

Luthar, Cicchetti and Becker (2000) describe resilience as a dynamic process whereby individuals exhibit positive behavioural adaptation when they encounter significant adversity, trauma, tragedy, threats, or even significant sources of stress.

According to Crawage (2005) there are a few characteristics common to many of the definitions of resilience. Firstly, it is about the ability to withstand quite severe contextual stresses and risks to development. Secondly, it is mainly the balance between, on the one hand, the stressors and risks that determine resilience and, on the other hand, the protective factors which might be operating. This means that, although exposed to stressful circumstances, some people manage to maintain well-being. They do so because of their own strengths, as well as because of the social support they receive from their environment. Thirdly, resilience can even be strengthened by experiences of adversity. Finally, resilience may be found in a

person, group or community and may strengthen their lives. In this study resilience refers to both internal strengths and external, environmental protective factors.

The ability to bounce back after times of adversity, high positive emotionality and resilience as a multi-systemic property are discussed below.

3.8.7.2 Resilience – growing from challenging emotional experiences

Tugade and Fredrickson (2004) describe psychological resilience as an ability to bounce back from challenging emotional experiences by utilising flexible adaptation methods to cope with the demands of stressful experiences. They state that research finds resilient individuals to be zestful, open to new experiences, optimistic and with high positive emotionality. As an important element of psychological resilience, positive emotionality emerges. Tugade and Fredrickson (2004) view highly resilient people as individuals that cultivate their positive emotionality proactively by using a sense of humour, optimistic thinking and relaxation techniques.

3.8.7.3 Positive emotionality is a key trait of resilient individuals

Tugade, Fredrickson and Feldman-Barrett (2004) explain that high positive emotionality is a key trait found in resilient individuals. These individuals have the capacity to bounce back from negative situations despite threats being made against them. It is possible that resilience is not just a psychological phenomenon. There are strong implications from research in health psychology that a person's self-perception of resilience could be indicated in a person's bodily responses to stressful stimuli. It could, for example be considered that health researchers examine subjective reports of psychological resilience as a possible prediction to one's physiological response to stress.

Tugade and Fredrickson (2002) state that for trait-resilient individuals, the experience of positive emotions is related to accelerated speed in rebounding from the cardiovascular activation generated by negative emotions+ (p.173). It is possible that a positive individual who regains his or her normal heart-rate and blood pressure quickly after an emotional shock simultaneously gives his or her body enough restoration time so that it can toughen up for more stressors, should they arise. The recurring benefits of a positive emotional experience can accumulate, since resilient individuals have positive emotionality.

3.8.7.4 Resilience – a multi-systemic property

According to Morano (2010) resilience is a complex multi-systemic property that develops over a life span. She explains that resilience requires comprehension of familial, individual and contextual factors that occur during, before and after the time of trauma. It seems that resilience does not originate from rare qualities but rather from ordinary human systems that arise from the minds, bodies and brains of people, religions, cultural traditions and relationships in the family.

According to Maier and Watkins (2010), it is well-known that the degree of behavioural control that a person has over a stressful event modulates the neurochemical consequences of exposure to the event. These authors review recent research in which it was found that the experience of control over a stressful event changes how an individual responds to future stressful events as well as how the stressor is managed.

Worthington and Scherer (2004) explains that, when an individual experiences constant stress, pro-inflammatory cytokines (cytokines are protein-like materials that are secreted when an infection or injury is sustained or when a person experiences stress) are increased and the intercellular immune system can become ineffective. Brain functioning, the cardiovascular system and the immune system are likewise negatively affected by the over-production of cortisol. Stress increases cortisol secretion. An individual who has the mental resilience to decrease his or her stress levels alleviates these problems and consequently builds physical resilience.

Kralik, Van Loon and Visentin (2006) found that resilience is a key factor in the transitional process of learning to adapt to a chronic illness. These authors found that provision of connected care is essential for successful management of chronic illness and resilience. It means that focusing on building a community via connected care, as well as creating a sense of belonging for chronically ill people is important for their resilience. Therefore, positive change, from a rather dire situation to a more positive and bearable situation, can take place through resilience.

3.8.8 Religion and spirituality

Religion is said to be knowledge, it is said to be ignorance. Religion is said to be freedom, it is said to be dependence. Religion is said to be desire and it is said to be freedom from all desires. Religion is said to be silent contemplation and it is said to be splendid and stately worship of God. Spilka, Hood and Gorsch, (1985, p. 30).

In the past twenty years research interest in the psychology of spirituality and religion has increased dramatically (Klaassen, Graham & Young, 2009). Spiritual and religious coping are particularly attractive to psychologists because it seems to have a mediating influence of superordinate, proximal, personality-level variables. Klaassen et al. (2009) found that many research efforts attempt to strengthen the support for this construct while it explores the strategies through which it manifests itself in people's lives. In the process, relatively little attention has been paid to the relational and social context in which the construct of spiritual/religious coping takes place (Klaassen, et al., 2009).

Researchers debate the nature, value and goals of spiritual coping. Pargament (1997) defines religiousness as a search for significance in ways related to the sacred (p. 32). Pargament (1999) defines spirituality as a search for the sacred (p. 12). Religiousness is defined by the search for objects of sacred significance, but spirituality is, in contrast, rather seen as a search for the sacred.

The unique aspects of religious and spiritual coping have been differentiated from other forms of coping (Pargament, 1997). At a level of defining these constructs, it implies that religious and spiritual coping is unique because both spirituality and religiousness concern themselves with something sacred. Religion is according to Pargament (1997) the feelings, acts and experiences of individual men/women in their solitude in as far as they comprehend themselves to stand in relation to whatever they may consider the divine+(p. 5).

3.8.8.1 Religion: the sacred and significance

Pargament (1997) defines religion as the search for significance in ways related to the sacred+ (p. 32). Religion is concerned with transcendent forces, supernatural beings, deities and God. It is said that religion is most typically concerned with the way in which people come to terms with ultimate issues in life. Religion refers to a specific belief, practice, idea or entity.

Religious experiences cannot only be seen as important for the painful times of living. It can also not only be viewed as a way of coping. The question arises whether religion is expressed more frequently in difficult times than in less difficult times. Higher levels of anticipated religious coping were found among college students in a response to scenarios that involve threat and loss (Bjorck & Cohen, 1993). Another study conducted by Pargament and Hahn (1986) found that participants turned to religion when they were confronted with negative outcome events. They also found that the participants viewed religion more as a source of support for difficult times than as an antidote to an unfair world or as a moral guide or even as an emotion of thankfulness in happy occasions.

Pargament (1997) refers to another study where it has been found that fishermen used more religious-like rituals for longer fishing trips than for shorter ones. It seems that these behaviours are linked to a response to anxiety and danger levels surrounding longer excursions. It therefore seems that several studies provide clear signs of more religious activity in difficult circumstances. Pargament (1997) suggests that people appear to involve religion to a greater extent when they are in stressful situations.

3.8.8.2 Religion functions at three different levels

According to Pargament (1997), religion functions at different levels. People that are religiously involved and committed use religious coping at a personal level. At a situational level, situations that are serious, threatening or harmful usually lead to religious coping. Finally, though little evidence is available on this topic, the relevant studies done suggest that religious coping is more prominent in cultures and congregations that are constantly involved in religious activity.

3.8.8.3 Interrelatedness between religious pathways

Pargament (1997) explains the interesting interrelatedness found between religious pathways. These pathways are said not to stand independently in relation to religion, but are characteristically different. Religious pathways might differ in their *connectedness to the sacred*, which is the way in which the individual chooses to experience the divine such as prayer, rituals and symbols. According to Pargament (1997) these practices might have different associations for different individuals.

Pargament (1997) continues to explain that religious pathways might also differ in the *importance and embeddedness* they have in an individual's life. Some people view religion as an overarching perspective on life, whereas other people view religion as relevant only in certain situations. Furthermore, different religious pathways are formed in different ways. Some people accept a religion as it is passed down to them and others might view religion uniquely through personal questions and searches (Pargament, 1997).

Pargament (1997) emphasises, however, that the distinctiveness of religious pathways should not be allowed to overshadow its common goal, namely a method in which an individual can seek significance. Valued endings are looked for in most, if not all, religious pathways and this is their greatest shared characteristic. Religious coping is used to find significance in a way not unlike that in which relationships may be used.

According to McCullough and Tsang (2004), certain psychologists see religion as a way to promote mental health. They state that Allport saw mature religion superior to other philosophies in that religion is the search for value in all things. Because of the comprehensiveness of religion, it allows the structuring of an individual's life in an integrated way.

3.8.8.4 Positive correlation between religion and health

Recent studies done by Koenig, Larson and McCullough (2001) found positive correlation between religion and specific indexes of physical and mental health (McCullough and Tsang, 2004). They found that religiousness led to lower forms of depressive symptoms, higher subjective well-being and even a longer life. Other social attitudes such as tolerance towards others were also related to religiousness. Religion could therefore encourage social harmony and individual health.

According to Peterson and Seligman (2004) spirituality can be observed as a universal concept. They say that although the specific content of spiritual beliefs varies, all cultures have a perception of an ultimate, transcendent, sacred and godly force. Very little research is being done on spirituality. A possible explanation for this may be that the concept of spirituality does not fit neatly into current research moulds.

McCullough and Tsang (2004) discuss spirituality as "the feelings, thoughts and behaviours that arise from search for the sacred without the added components of non-sacred goals and religious community" (p. 347). Since it has successfully been demonstrated by Pargament (2002a, 2002b) that spiritual or religious coping differs significantly from previously-identified coping strategies, ample opportunity remains for spiritual or religious coping to be investigated in terms of health-related topics.

Krägeloh, Pei Minn Chai, Shepherd and Billington (2010) compared the ways religious coping is used to the ways other coping strategies are used. Krägeloh et al. (2010) state that religious involvement has a significant positive impact on

psychological health. Exactly how these effects emerge is still unclear. Religion seems to have a positive effect on well-being because it can be a resource in dealing with adversity. It is still being investigated why religious coping, relative to other coping strategies, is so functional.

3.8.8.5 *The absence of problem- or emotion-focus in religious coping*

Krägeloh et al. (2010) explains that religious coping could not clearly be classified as either a problem-focused or emotion-focused coping strategy. If religious coping plays a different role, depending on the level of the religious or the spiritual beliefs of an individual, it may correlate differently to secular coping strategies.

Participants with higher levels of religious or spiritual coping were most related to active coping strategies and least related to maladaptive ones (Krägeloh et al., 2010). The exact opposite was found to be true for participants with low levels of religiosity or spirituality. This study also found that religious coping tends to be used in a problem-focused manner with higher levels of spirituality and religiosity.

According to Krägeloh et al. (2010), this means that a person can use spirituality or religion to gather resources on finding a solution to whatever might cause stress. In individuals displaying lower spirituality or religious levels, religion and spirituality seem to be associated with avoidant coping strategies, such as denying the problem. Individuals with extrinsic religious orientation seem to use desperate religious strategies in times of stress. People with intrinsic religious or spiritual orientations, where religious coping is not motivated by immediate personal needs, have more deeply rooted belief systems (Krägeloh et al., 2010).

Pargament (1997) states that every religious coping effort represents a response to values under fire, values that are tested, endangered, or lost through life's events. Every religious coping effort has a common end, the enhancement of significance+ (p. 198).

3.8.8.6 *Coping and religion are two separate concepts*

Coping and religion are two separate concepts and should not be mistaken for each other. Religion does not always play an important role in problem solving (Pargament, 1997). However, religion can also not be reduced to a complete negligible role. In fact, religion seems to become a focal point in the critical situations of life. Pargament (1997) continues to explain that religion does not come out of nowhere. Its entrances (and exits) are, at least in part, predictable and understandable (p. 162). People use religion to cope because religion offers a more persuasive avenue to significance than non-religious alternatives.

3.9 Chapter conclusion

The purpose of this chapter was to explore the theoretical paradigm of positive psychology and to examine seven specifically identified positive psychology constructs. Most of the research was done in Western and developed countries and may not be applicable in other cultural environments. Contributions from major theorists e.g. Antonovsky (1979), Csikszentmihalyi (2000), Lopez, Seligman (2003) and Snyder (2004) and Strümpfer (2005) are reviewed and included to orientate the reader. First, the development and definitions of positive psychology; Antonovsky's theory of salutogenesis and the salutogenic paradigm of positive psychology are explored. A historical background of positive psychology is given and recent contributions to the field of positive psychology are addressed.

Seven positive psychology constructs are included according to the applicability of the research to the topic of the study. The constructs that are explored are positive coping, search for meaning, benefit-finding, hope, sense of humour, resilience and religion and spirituality.

The next chapter includes the ontology and epistemology of qualitative research design and explains how the research was conducted. Procedures and steps that were taken to collect the research narratives follow. The research questions and

aims, the selection of participants, data collection, existing programmes and models and the data analyses are discussed. Ethical considerations of the research are highlighted and the entire process is discussed.

Chapter 4

Conducting the qualitative research

4.1 Purpose of the chapter

The previous chapter, chapter 3, describes the constructs and concepts of positive psychology theoretically and explains its applicability to the current research challenge, the understanding of the psychological well-being of TM patients.

Chapter 4 introduces interpretative phenomenological analysis (IPA) as the research paradigm for this study and discusses how qualitative research was conducted in addressing the research problem. From the perspective of positive psychology the fortigenic qualities of TM patients, which enable them to cope with their neurological disorder, were explored to develop a coping model for their well-being.

In giving an overview of the research process of the study, theoretical guidance from the literature is briefly referred to in each step. The ontology and epistemology of the qualitative research is discussed, the methodology is explained and the interpretative phenomenological analysis (IPA) used in the study is discussed. The credibility of qualitative research is tested and accounted for.

4.2 The research problem of this study

As alluded to in the motivation for the study in chapter 1 and illustrated in the intermediate treatise, there seems to be very limited psychological care to use in concert with established medical regimes in assisting TM patients to cope with the disability or painful effects of the disease. This research needs to establish which strengths patients can utilise to cope with the challenges presented by this illness in their daily lives. The theory of positive psychology with its emphases on fortigenic

qualities presents a way to identify possible, if not probable, coping living styles for TM patients.

4.3 Objectives of the research

The objectives of this study are to:

- Explore the coping strategies of patients with transverse myelitis,
- determine which coping strategies are most likely to successfully assist sufferers in their daily dealing with TM and
- develop, based on the analysis, a coping model for the well-being of patients with transverse myelitis.

4.4 Research paradigm

Interpretative phenomenological analysis (IPA) is a phenomenological approach in that it seeks an insider perspective on the lived experiences of individuals and interpretative in that it acknowledges the researcher's personal beliefs and standpoint and embraces the view that understanding requires interpretation (Smith, Jarman & Osborn, 1999). Smith et al. (1999) stress that the purpose of IPA is to attempt as far as possible to gain an insider perspective of the phenomenon being studied, while it acknowledges that the researcher is the primary analytical instrument. The researcher's beliefs are not seen as biases to be eliminated but rather as being necessary for making sense of the experiences of other individuals.

Biggerstaff and Thompson (2008) state that IPA has been specifically developed to allow rigorous exploration of idiographic subjective experiences and social cognitions. IPA's theoretical underpinnings stem from the phenomenology which originated with Husserl's attempts to construct a philosophical science of consciousness, with hermeneutics (the theory of interpretation) and with symbolic-interactionism. This posits that the meanings an individual ascribes to events are of central concern but are only accessible through an interpretative process (Biggerstaff

and Thompson, 2008). IPA acknowledges that the researcher's engagement with the participant's text has an interpretative element, yet in contrast to some other methods, for example discourse analysis (DA) (see Potter, 1996), it assumes an epistemological stance whereby, through careful and explicit interpretative methodology, it becomes possible to access an individual's cognitive inner world. IPA explores how people ascribe *meaning* to their experiences in their interactions with the environment (Biggerstaff & Thompson, 2008).

The aim of IPA is to explore how participants are making sense of their personal and social worlds and the meanings particular experiences, events [and] states hold for participants+ (Smith & Osborn, 2008, p. 53).

Phenomenological inquiry can be divided into two methods of research, namely descriptive and interpretive phenomenology. The aims with a descriptive approach are to search for general, rich descriptions of lived experience and to strip away prior experiential knowledge which could influence the process of research. This approach focuses on a description of the phenomenon under study, free from any biases, prior knowledge and highlighting common features (Human, 2012).

The present study aims to understand the phenomenon under investigation and to make sense of and attach meaning to experiences in this wider context (Biggerstaff & Thompson, 2008; Human, 2012; Smith & Osborn, 2008). Crist and Tanner (2003) state that hermeneutic interpretive phenomenology is a qualitative research methodology and is used when the research question asks for meanings of a phenomenon with the purpose of understanding the human experience.

Interpretative phenomenological analysis (IPA) was employed in this study to explore individuals' experiences of TM. IPA was used because it highlights the links between participants' talk, cognition and behaviour (Smith, 1996). IPA lends itself to psychological research because it supports the social cognitive paradigm. It reflects a belief in and concern with, the chain of connection between verbal report, cognition and physical state+ (Smith, Jarman & Osborn, 1999, p. 219). IPA holds a promise for the exploration of meaning and sense-making of lived experiences (Smith & Osborn, 2003). Willig (2001) proposes that IPA works with any texts that

are generated by participants in, for instance, the form of personal records and personal life stories.

4.5 Research design of this study: qualitative research

4.5.1 Features of qualitative research

Within the described phenomenology (IPA), qualitative research is the encompassing research method that was used in this study. Qualitative research typically reports detailed insights into the worlds of participants (Hoepfl, 1997).

According to Del Fabbro (2006) qualitative research emphasises the actions, events and the meaning of experience through the eyes of certain participants, researchers and groups and is sensitive to the specific contextual nuances of the study topic, as well as the relationship between participants and researcher/s and its significant impact on the interpretation of the results.

Hoepfl (1997) suggests eight features of qualitative research:

- A qualitative researcher acts as a human instrument of data collection.
- Qualitative researchers are interested in the pervasive as well as the idiosyncratic, while they are seeking the uniqueness of every respective case.
- Qualitative researchers attempt to describe, observe and interpret settings exactly as they are while maintaining empathic neutrality.
- Qualitative researchers attempt to focus on an emerging process as well as the outcomes of the research.
- Qualitative research mainly uses inductive data analysis.
- Qualitative research is characterised by the discovery of meaning of events for both the individual and the interpretation for the researcher.
- Qualitative research is emergent rather than predetermined and the focus of researchers is on what emerges and on what can be gained from that.
- Qualitative research has special criteria which are applied to ensure credibility.

4.5.2 Inconcludability, indexicality and reflexivity

According to Patton (1990), these features are interconnected. Henwood (1996) notes that quantitative research focuses on measuring, specifying and manipulating relationships between given variables to test causal hypotheses. Del Fabbro (2006) explains that the differences between qualitative research and quantitative research lie in three %methodological horrors+ (p. 187). These %horrors+ are inconcludability, indexicality and reflexivity.

In terms of ***inconcludability***, Del Fabbro (2006) notes that qualitative research accepts the inconcludable character of many fields of research. While quantitative research addresses a %problem+ by using a statistically representative sample size to statistically derive conclusions, limited and single case studies are acceptable when conducting qualitative research. Qualitative research regularly provides in-depth examinations, deductive results and sound conclusions of the meanings that were found in various contexts. The research therefore contributes to diversity of meanings rather than generalised conclusions.

In terms of ***indexicality***, Del Fabbro (2006) notes that %an explanation is always tied to a particular context and will change as the context changes+ (p. 187). This forms the point of departure and determines foci of exploration in qualitative research. In quantitative research, in contrast, such natural contexts would be viewed as problematic as it precludes the statistical validation and reliability analysis and assertion that are characteristic of quantitative research. Qualitative research does not intend to generalise findings but provide an in-depth understanding of the phenomenon within its natural context.

As far as ***reflexivity*** goes, Del Fabbro (2006) highlights the significance of the researcher's interpretation of the topic and the findings. The researcher forms part of the research process and interprets the data according to his or her own frame of reference. This places a responsibility on the researcher to manage his or her own subjectivity in the research process, but simultaneously exploits the researcher's

fervour in conducting specific research. Quantitative research on the other hand is interested in a scientific methodology of repeated measurements, the testing of hypothesis, dependent and independent variables and internal and external validity.

4.5.3 The ideographic case-study approach

According to Ratcliff (2006) qualitative research has many qualities and can be done from various theoretical perspectives. The *ideographic case-study approach* was viewed as basic method for this study. Small samples of participants are used in the ideographic case-study approach. It enables the researcher to record an exploration of themes shared between cases (Ratcliff, 2006). This procedure was particularly useful in this research study because, as in this study, new models are desired outcomes of this kind of procedure.

Bryman (1988) says that qualitative research offers the researcher the opportunity to develop an idiographic understanding of participants and what it means to them, within their social reality, to live with a particular condition or be in a particular situation.

Reid, Flowers and Larkin (2005, p. 20) posit that to understand experience is the very bread and butter of psychology and ... offers psychologists the opportunity to learn from the insights of the experts . research participants themselves+. The broad premise of positive psychology creates a scope for IPA research to become less disease- and deficit-focused and for participants to be given a chance to express their views about strength, wellness and quality of life+(p. 21).

According to Hoepfl (1997), the aim of phenomenological qualitative research is to understand certain phenomena in specific contexts. Strauss and Corbin (1990, p. 17) state that qualitative research means any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification+.

4.6 Research procedures utilised in this study

4.6.1 Method of data collection

The selection of an appropriate method of data collection depends upon the aim of the study (Marshall, 1996). In this study stories, by e-mail, were used as methods of interaction between the participants and the researcher. This accelerated the process whereby the researcher could achieve understanding of participants' perspectives on their daily lived experience (Patton, 2002).

An e-mail method of data collection was attractive because the number of people suffering from TM in South Africa is small and they are spread widely over the vast country. The cost in time and finances of face to face interaction would have been prohibitive to the researcher, even though the number of available participants was relatively small. Electronic correspondence was furthermore chosen in a bid to collect the data with minimal disturbance to the participants during their suffering. Lengthy telephone conversations could be inconvenient and tiresome for the participants because of pain and associated conditions. In communicating by e-mail they have control over the scheduling and pace of their responses. They could formulate their response over time and interrupt a sitting if they needed to do so.

Although e-mail communication is not similar to a face- to- face interview as such, it also represents a social situation and inherently involve a relationship between the researcher and the participant (Charmaz, 2000, p.525). An important spin-off of the non-prescriptive gathering of information is that it renders the research "more open-minded and less structured, since the researcher is interested in learning more about the perspective of the person being interviewed+(Merriam, 1998, p.73).

4.6.2 Selecting participants

The list of all 35 TM patients in South Africa who are known to the South African TM Support Group and who form the membership of this group was available.

Permission was obtained from the Chief Administrator of the TM Support Group to use this list to select potential participants for the study. Ten potential participants from this list were consequently selected by means of *purposive sampling*. Purposive sampling is "selecting information-rich cases for study in depth" (Patton, 1990, p. 169). Purposive sampling is best used with small numbers of individuals which may well be sufficient for understanding certain human perceptions, problems, needs, behaviours and contexts.

In this study participants were screened in terms of their exposure to TM and their ability to convey their experiences effectively. They should have been diagnosed with the disease and subsequently have been experiencing the symptoms of the disease for at least five years. They should furthermore have the ability and facilities to formulate and convey their stories in this regard. Pragmatically this meant that they should have access to e-mail as potential participants were widely dispersed over a vast country.

The ten purposefully chosen adult patients were telephonically approached to request them to participate in the study. Five potential participants were excused from the research. One appeared reluctant and somewhat uncomfortable with the idea of participating in the research, two were not available because of other commitments and the other two excused persons were too ill to participate in the research. Eventually, two adult females and three adult males between the ages of 26 and 58 and suffering from TM for at least five years, took part in the research.

For ethical reasons, the participants were ensured of their anonymity. The researcher never met the participants in person and did not endeavour to determine irrelevant (to the study) personal information such as race, religious connotation, creed or sexual orientation. They were also told that they could at any time, if they wish, withdraw from participating.

4.6.3 Process of data collection

After identifying the research participants, the researcher e-mailed formal consent forms that were pre-approved by the Ethics committee of the Faculty of Humanities of the University of Pretoria, to the participants (see Annexure H). The consent forms were accompanied by similarly approved information sheets (see Annexure I). The forms were completed and signed by them and were returned to the researcher by e-mail to confirm that they voluntarily agreed to partake in the study.

After obtaining biographical information, participants were requested to write their stories of their world with TM and to send it to the researcher by e-mail. Participants were not requested to write specifically about their coping strategies. It was an open assignment. The consent form, however, stated the title of the thesis and alerted the participants to the main focus of the study was. Even though they told the researcher about their various adversities, they also wrote about their coping strategies.

Two participants wrote in English and three in Afrikaans. It was fortunate that the researcher is fluent in both these languages and no translators were required. The researcher could present research material and results in English to be included in this thesis, while continuing the Afrikaans interaction seamlessly where applicable.

The participants were informed that their stories could be any length and that they could e-mail their stories whenever it suited them. After one month the researcher received all five stories, varying in length between two and ten printed pages (see Annexures C to G). One participant decided to write two stories, six months apart. His first story contained a detailed outlay of the chronological course of all the medical symptoms and experiences. His second story was about his emotional experiences regarding his life with TM. The participants were not urged to pay attention to their coping strategies as such. They were merely requested to write about their experiences with TM.

Where the researcher, after receiving the narratives, needed clarification regarding wording, concepts or nuances in the stories, the participants were e-mailed and meanings were confirmed. (At a later stage telephonic conversations were conducted with each participant to review the researcher's clustered themes and interpretations of all their stories to re-verify the accuracy of the researcher's initial

understanding.) After all uncertainties were cleared, the researcher used interpretive phenomenological analysis (IPA) to interpret the stories.

4.6.4 Data analysis

The analysis of the data in this study was based on the recommendations of Smith et al. (1999), who suggest two methods of analysis in IPA. The first alternative is to generate a list of main themes from the first participant and then to supplement this master list with more themes as the analysis is continued with other stories. The second option is to generate a new master list of themes for each individual case. In this study the second approach was used to allow a greater richness of themes to emerge from the data. Initially the data were read several times by the researcher and two independent co-interpreters (both registered psychologists) to find themes expressed by TM patients. The schedules and circumstances precluded conferences where all three interpreters were present. The researcher had the task of conferring (telephonically, by e-mail and in person) with each co-interpreter in turn until she was sure that all were in agreement regarding the themes and other conclusions.

Several different themes were listed and possible connections between the themes were searched for. Regular revisiting of the data transcripts ensured that themes remained close to the primary source data. A master list of themes was created for each individual participant.

Analysis in IPA is a dynamic and cyclical process (Smith et al., 1999) so each phase involves checking and rechecking the original data for evidence of the emerged themes. This is done to ensure that all themes that there was evidence for were identified. Text examples that led to the many different themes were re-examined several times to ensure they best represented all the themes in question. Co-interpreters assisted the researcher to recheck and discuss all the themes.

As this phenomenological research is about exploring each respondent's perceptions of what is important in relation to their experience of TM, the researcher and co-

researchers attempted to consciously avoid asking questions about issues that the participants did not mention in their stories.

To ensure the anonymity of the participants when quoted, it was considered to simply call them Participants A, B, C, D and E on a *first-come-first-tagged* basis. It was then opted to add three more letters to each of these alphabetic *handles* to form common *English* names. These names are therefore non-descriptive and without any connotation, but re-humanise the participants as story-tellers. Please meet our participants **Anne**, **Bert**, **Cate**, **Drew** and **Eric**.

According to Aronson (1994) ideas coming from conversations with several participants will invariably merge. Smith and Osborn (2007) found that meaning is central to qualitative research and that it is important to understand the content and complexity of meanings especially after the collecting of data with a flexible data instrument. In this study the flexible data instrument is the collection of stories of TM patients' experiential encounters with TM.

The first step in the analysis of the narratives was to identify the data elements and catalogue themes. Themes were defined as units derived from patterns such as conversational topics, vocabulary, recurring activities, meanings and feelings. Themes were identified by bringing together components or fragments of ideas or experiences, which could frequently each be regarded as quite unremarkable when viewed in isolation.

Secondly, the themes that emerged from participants' stories were categorised to form clusters giving meaning to experiences and forming patterns of experiences.

Thirdly, after the clusters of the emerging themes were thoroughly reviewed and identified for every participant, each cluster was analysed and evaluated in terms of its relation to the seven constructs of positive psychology, namely positive coping, searching for meaning, benefit-finding, hope, sense of humour, resilience and religion and spirituality.

Finally, the findings of all the participants' themes contributed to the design of a coping model for patients suffering from TM. Though the constructs of positive psychology played a role in the design, it was the voice of the participants, their ideas and their needs that contributed to the construction of a coping model.

In analysing the data, the researcher worked in concert with two clinical psychologists (both registered as such by the Board for Psychology of the Health Professions Council of South Africa) to enhance the base for objective evaluation and to minimise the chances of overlooking valuable constructs. The collaboration in analysis was done in the form of discussions and evaluations of the emerging themes, as well as in the process of clustering the themes.

4.7 Credibility of the data

4.7.1 Criteria for credibility

Marshall and Rossman (1995) state that the criteria that are used to evaluate qualitative research are:

- *Transferability*, which addresses how transferable and applicable the findings are to another group of people or settings.
- *Confirmability*, which addresses whether the findings are reflective of the subjects without the researcher's own prejudices.
- *Dependability*, which addresses the degree to which the same results would ensue if the study was again conducted with the same participants and in the same context.
- *Credibility*, which addresses whether the study was done in such a fashion that the subject was described and identified accurately (Marshall & Rossman, 1995).

In this study care was taken to meet these criteria as far as it was possible without prejudicing the goals of the research.

- The methods used in this study and some of the findings will indeed be applicable to other groups of people or settings, but as the study was specifically aimed at the coping constructs of patients with TM in the realm of the South African TM Support Group, claims for the credibility of results will not be beyond that setting without careful consideration of differences between groups and settings.
- Conformability was placed on a strong footing in this study, as detailed in subparagraph 4.7.3 below.
- Dependability as described above by Marshall and Rossman (1995), is a big ask in the light of the ancient observation of Heraclitus that it is impossible to swim in the same river twice. In this project the data was repeatedly analysed over a period of time by more than one researcher to strengthen the dependability of the results.
- Credibility is the criterion of qualitative research that the remainder of paragraph 4.7 is dedicated to.

To clarify these statements, it must be stated that qualitative research is context specific. It therefore, takes the position that situations can never be precisely simulated (Finlay, 2006). For instance, what emerges in a narrative is seen as subject to the researcher's approach, as well as the unambiguous interviewer-participant relationship context. A next researcher, or even the same researcher that approaches the same participant at a different time or place, would not bring out precisely the same story (Finlay, 2006). Because of the time allowed to participants in the study to construe their stories in their own settings over a period determined by them self, effects of this observation of Finlay would be less pronounced here, though still present.

Qualitative research includes subjective interpretations by both participants and/or researchers. Since interpretation cannot be excluded from the research process, any analysis can only be presented as a tentative statement with a limitless field of possible interpretations (Finlay, 2006), although the team approach rendered this effect also less pronounced here.

Qualitative researchers do not intend to produce results that are generalisable because the intention is not to identify general patterns among populations. Instead, they are concerned to show that findings *can* be transferred and *may* have meaning or relevance if applied to other individuals, contexts and situations. Therefore, qualitative researchers may well commemorate the depth and richness of data that can possibly be obtained from just one or a few participants who have been purposely approached.

Qualitative researchers need to show their readers whether they are primarily seeking rigour or relevance; accuracy or poetic artistry; trustworthiness or resonance. The work can then be judged *on its own terms* (Finlay, 2006). Relevance and credibility (trustworthiness) carries the main focus in this research.

4.7.2 Purposive sampling

Purposive sampling was used in this study to ensure that potential participants with a wealth of knowledge and experience relevant to the research question were selected for the study. Further screening ensured that such potential participants that were simultaneously qualified, willing and able indeed took part in the study. The sampling method contributed to ensure that collected data matched the research criteria of relevance, namely to find the fortigenic qualities of TM patients which enable them to cope with their neurological disorder.

The quality and richness of collected data bore witness to the premise that the sample size was adequate, yet pragmatic. The data carried sufficient information in a collection of information laden stories from five participants to enable researchers to gain invaluable understanding of TM patients' adversities and coping strategies.

Patton (2002, p. 242) states that *cases from which one can learn a great deal are of importance and therefore worthy of in-depth study*. A principle of this sampling technique is to specifically select information-rich cases. In this study this resulted in the collection of five detailed stories that were collected over a four week period from TM sufferers. The participants were not given any details of other participants and

were geographically widely separated. As far as can be deduced there was no interaction between participants in preparing stories for the purposes of this study. All participants remained unaware of the identities of any other participants.

4.7.3 Conformability

Lincoln and Guba (1985) investigated methods for ensuring the credibility of research results after posing the simple question: "How can an inquirer persuade his or her audiences that the research findings of an inquiry are worth paying attention to?" (p. 290). They found that, in conventional research, external validity is about the ability to generalise findings across diverse settings to create working hypothesis from which conclusions can eventually be drawn. This was reflected in the qualitative setting of this study by the identification of themes by a team of interpreters.

Lincoln and Guba (1985) argue that "since there can be no validity without reliability (and, therefore, no credibility without dependability), a demonstration of the former is sufficient to establish the latter" (p. 316). They, however, provide a measure which might add to the dependability of qualitative research, namely the use of an "inquiry audit," in which reviewers check both the method and the product of the research for consistency (p. 317) to ensure the "confirmability" of the research. In a sense, they refer to the extent to which the researcher can exhibit the neutrality of the research interpretations, through a "confirmability audit." This is echoed by the opinion of Hoepfl (1994) that one can make the creation of segments of the raw data available for others to analyse.

The "conformability" of the current research project was ensured in several ways. Firstly, the stories in the original format in which they were presented to the researcher were studied by every member of the interpreting team. Members of the team acted as immediate reviewers of the work of each other and made their findings available to each other for further review until consensus was reached. The consensus results were taken up in this documentation for further review by promoters and then remain open for review by other qualified interested parties. In

this way the e-mailed narratives unwittingly assist in the credibility assurance system by forming a retraceable paper trail of the research.

In addition to this Hoepfl (1994) also noted that a researcher may make use of member checks, in which participants are asked to confirm the findings. This took place in two phases of the current research, firstly when all uncertainties and ambiguities concerning the wording of stories were addressed by interactive e-mailing and more importantly when emerged themes were discussed with participants telephonically.

4.7.4 Establishing the insider's perspective

Smith (1996) and Smith et al. (1999) describe the aim of IPA as the exploration of participants' views of and adaption to their worlds. IPA is about receiving and understanding an insider's perspective. It requires the qualitative researcher to be attentive to various aspects such as one's own linguistic, social and cultural perspectives as well as the different perspectives of participants (Patton, 2002).

The IPA method can be evaluated in terms of how it addresses the interpretative nature of the analysis and by assessing how successfully the researcher's observations are grounded (Willig, 2001). Consequently, credibility (trustworthiness) and consistency (equivalent concepts to validity and reliability in the quantitative research paradigm) are intrinsically linked with the broader epistemology (philosophical theory of knowledge) of this form of qualitative research.

In conventional research "internal validity" refers to the extent to which the findings truthfully express reality. The corresponding construct in qualitative research, namely credibility, depends less on sample size and more on the analytical abilities of the researcher to interpret the richness of the information gathered (Hoepfl, 1994). Credibility means that it is the voice of the participants that is heard and not the voice/theory of the researcher. That the researcher interprets the data as it is without adding too much of his or her own dynamics.

The need for this study arose from a need of the researcher to obtain knowledge only available to the research participants. The co-interpreters had no previous knowledge on the specific coping plights of patients with TM either and it was less likely for the pre-conceived ideas of an interpreter to dampen the combined voices of the participants. It must be acknowledged that the thinking patterns of interpreters are human and that the voices of researchers will always be present in their findings. Though, care was taken to ensure that this did not unduly influence credibility of results in this study. Additional credibility boosting strategies that were adhered to in this project are discussed below.

4.7.5 The role of the researcher: openness

When collecting and analysing the phenomenological data, the researcher engaged in a process of trying to see the world of TM patients from each differing perspective. The researcher engaged in this research because of a deep seated interest. As mentioned, the researcher became interested in the plight of TM patients when her daughter contracted the disease. After her daughter recovered fully in the year 2000, the researcher became administratively involved with the TM Support Group.

The previous TM Support Group leader fulfilled this role in an arms-length fashion and when the researcher took over she initially simply followed in her predecessors footsteps. She kept record of the contact detail of TM Support Group members. She supplied the patients with practical information such as neurologists' names and telephone numbers or the names of vendors of wheelchairs and similar equipment.

This mode of operation never brought her into physical or emotional contact with the patients and she developed a desire to play a closer role in assisting patients. She needed support in the form of a well-researched and developed, shareable coping model to help her in this venture.

As a result of this background, the researcher awaited participants' views with anticipation and eagerness and consequently attended to it with enthusiasm. Such involvement, according to Finlay (2006), is prerequisite to attaining the best results. Dahlberg, Drew and Nystrom (2001) state that openness explains the researchersq

skill to be open, aware, self disclosing, sensitive and willing to be surprised at how the phenomenon reveals itself. It is also about the researchers' capability to ask true phenomenological questions to which the researchers hold back their personal assumptions of the answers.

The researcher was prepared to open her mind freely to whatever was revealed by participants in this spirit of willingness to listen, see and understand without prejudice. The aim was to permit the data to present itself to the researcher instead of the researcher commanding preconceived thoughts on the data. This openness was maintained throughout the entire research process, not just at the start.

Van Manen (1997, p. 345) explains that a powerful phenomenological text thrives on a certain irrevocable tension between what is unique and what is shared, between particular and transcendent meaning and between the reflective and the pre-reflective spheres of the life-world. The researcher engaged in reflexive analysis (Finlay, 2003, 2005) to manage the described tensions. The researcher also moved back and forth in a kind of dialectic way between awareness and experience; between studying the smaller parts and the whole. While interpreting the stories, the researcher of this study acknowledged her own life experiences but deliberately stayed focused on the participants' experiences as well.

Dahlberg *et al.* (2001, p.94) warn that researchers should be careful not to make definite what is indefinite. In this regard, Wertz (2005, p.175) presents a graceful summary of phenomenological project handling that urge researchers not to misconstrue sentences to mean more than what was intended: Phenomenology is a low-hovering, in-dwelling, meditative philosophy that glories in the concreteness of person-world relations and accords lived experience, with all its indeterminacy and ambiguity, primacy over *the known*.

It is, therefore, worth emphasising that fine phenomenological research, draw attention to the *complexities and ambiguities* of participants' experiences Finlay, (2003). Phenomenological research is typified by its ability to present the paradoxes and to incorporate the contradictory statements of participants while this kind of research demonstrates holism (Dahlberg *et al.*, 2001).

To ensure quality research, the researcher also took note of such complexity, ambiguity and ambivalence in the relations of participants' experiences. To illustrate the pitfalls of interpreting statements too hastily or in isolation, consider the following sentences from two consecutive paragraphs by Anne: *"I truly believe that I am no stronger or wiser than anyone else I have met"* and *"I thank God that I am aware of the power of my inner strength."* There seems to be a measure of ambiguity and ambivalence in this data, or more subtle and complex nuances than immediately meet the eye. The researcher carried the responsibility to heed Dahlberg's warning not to draw conclusions hastily and thereby compromise the credibility of data.

Regarding the research design credibility it is essential to establish whether researchers actually observe what they think they observe and indeed hear the meanings that they think they hear. The internal credibility of qualitative research is, therefore, the degree to which the interpretations and themes attain meanings for the researchers that echo the consistent views and experiences of the participants and the researcher (McMillan & Schumacher, 1997).

4.7.6 Credibility boosting strategies

The argument for consistency and credibility in this project is strengthened by

- the documentation of the stages of analysis,
- the consensus reached between interpreters regarding the data after each one did an initial independently analysis and
- the deviant-case analysis that was conducted through the researcher who had to discuss all inconsistencies and non-typical responses with each co-interpreter until consensus was brought about.

Added strategies that strengthen the credibility claims of this study include:

- Participant interaction: The researcher verified the accuracy of the researcher's understanding informally by e-mail with participants after the initial data (stories) were collected and where any uncertainty or ambiguity existed.
- An unstructured individual participant review was telephonically done where the researcher asked each participant to review the researcher's clustered themes and interpretations of all their stories to re-verify the accuracy of the researcher's initial understanding.
- Multiple conclusions: Agreement and consensus on descriptive data interpretation were reached between the members of the interpreting research team, namely the researcher and two assisting psychologists.
- The researcher of this study made an effort to ensure that the phenomenon to be studied was clearly articulated and delimited.
- The rights of participants to confidentiality, anonymity and other ethical principles were discussed with all the participants and agreed on signed informed consent forms.
- The purpose of the research was clearly explained.
- The sample size was efficient to obtain rich data about the phenomenon within a reasonable length of time.
- The chosen sampling technique was purposeful to obtain information-rich participants.
- The research design specified the essential strategies such as the collection of personal stories together with the re-verifications with the participants for accuracy of the researcher's thoughts, understanding and interpretations.
- The chosen research design and methods were suitable for the emergent nature of the study.
- Strategies were in place to minimise potential observer effect and bias by involving other researchers and psychologists to verify findings.
- The logical extension and usefulness of the findings were employed in designing a coping model for TM patients and their care-givers.

4.7.7 Ethical considerations

The research was approved by the Ethics committee of the Faculty of Humanities of the University of Pretoria. Accordingly, the TM patients were involved in the research voluntarily and signed informed consent forms. The identity of participants was kept anonymous and data are dealt with confidentially.

4.8 Chapter conclusion

In this chapter, it is described how the research was conducted. The research problem is discussed and the objectives of the study are stated. The research design and procedures, including the participants, methods of data collection and analysis are discussed.

The credibility of the data and the research process are established and the steps that were taken to ensure consistency and credibility during the research process are explained. In the next chapter the results of the analyses of the collected research stories are discussed. The synthesis of the stories and clustered themes follow.

Chapter 5

In search of meanings

5.1 Purpose of the chapter

In this chapter the results of the data analysis are presented. This chapter aims to further the stated objectives of the research by recording the discovery of the coping qualities of TM patients through analysis of the collected narratives by the researcher and suitably qualified co-interpreters.

Data contributed by each participant is presented, before emerging themes from such data are discussed.

5.2 Order of events

The progress of the research as described below and in chapter 6 follows a certain order of events. The logic and chronologic order of events will vary however, since the development of both is continuously determined by confluences of ideas and themes and by conclusions from such ideas and themes. Some steps will be repeated participant by participant, while others will concern the whole group of participants. While the logic order of events is easier to describe and follow in a preview, the chronologic order describes the eventual progress better as seen below.

The logic steps are:

Biographical information of each participant is presented. Brief information regarding the relevant background and lived experiences of the participant is discussed. His or her physical, emotional and interpersonal situation in dealing with TM is presented.

Clustered themes based on the emerging themes are derived. The emerging themes as interpreted from the original data are attached as Annexurees K, L, M, N and O.

Summaries of TM coping strategies of each of the five participants are offered. From the clustered themes of the participants (*"the voice of the participants"*) *interpretations and rational deductions* are made. These are then compared with the seven constructs of positive psychology (*"the voice of theory"*) (Snyder & Lopez, 2002) to find alignment between theory and results. Where the comparison brings new ideas from *the voice of the participants* to the fore, these are documented as well. The results are then graphically presented to give the reader a rapid visual overview of the accompanying documentation.

Conclusions will be drawn from all of the above in the light of the objectives of the research.

A *model for coping* will be designed from the summarised descriptions as well as from the voices of the participants and from the proverbial *"voice of the theory"*. This model is presented in chapter 6.

5.3 The data and the themes: getting in touch with reality

5.3.1 Graphic representation of coping strategies

When themes have been described and the coping strategies of each participant have been identified, it is known which of the seven established coping constructs

and which additional coping strategies are readily used by each participant. A graphic representation regarding the coping strategies of each participant is given together with the results for each participant from sub-paragraph 5.3.3 below. Each graphic representation follows the design of the following template (Figure 5):

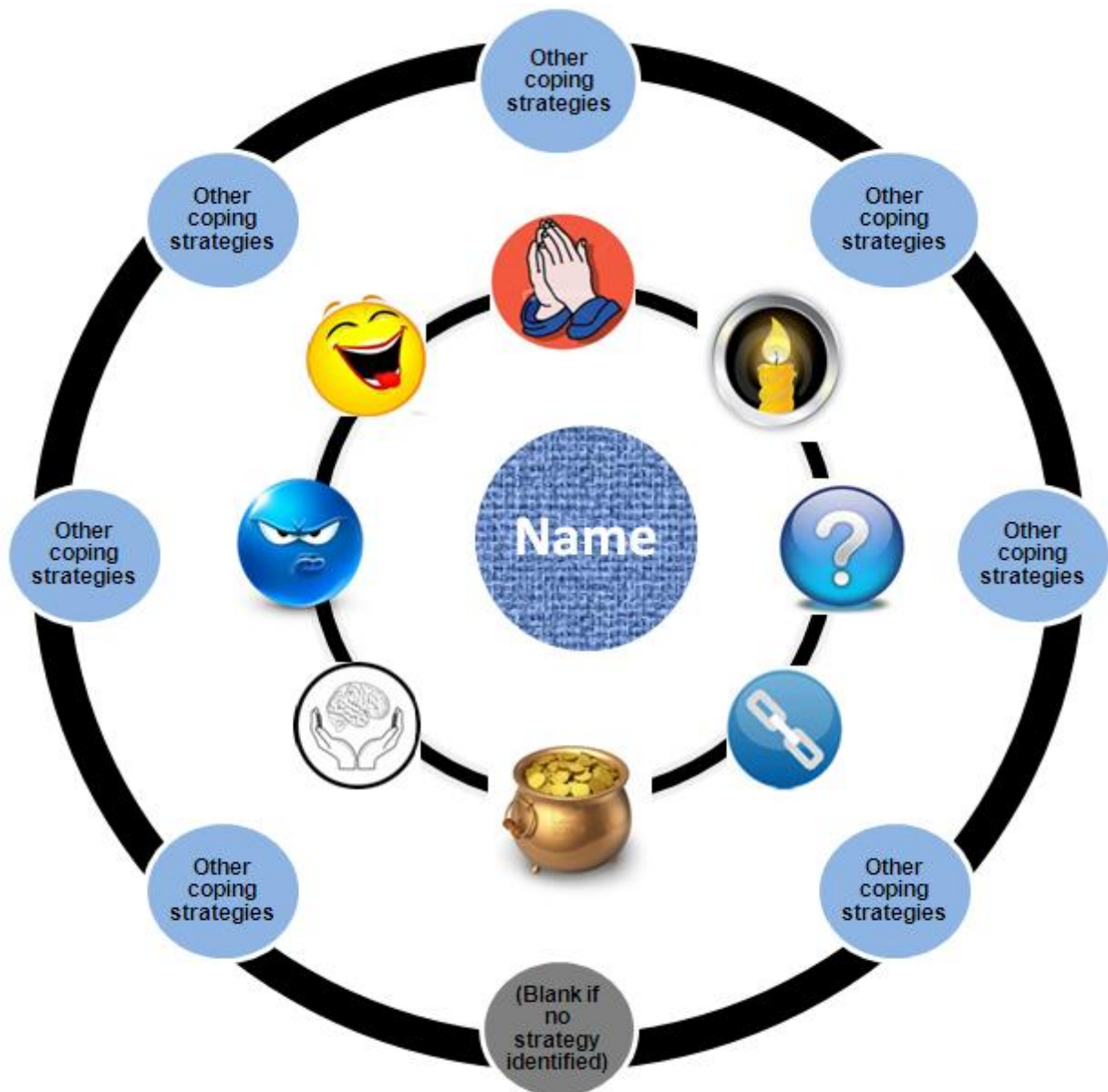


Figure 5: Coping graphic template

Each illustration consists of the following elements:

- The pseudonym of the specific participant shown in the centre,

- around it a ring consisting of only those of the seven established coping constructs that the participant uses according to the evidence. Each construct is represented by a symbol discernible from the keys from Figure 6, below. The size of any symbol in his or her graphic is indicative of the frequency and extent to which the participant uses the indicated construct according to the data and
- an outer ring showing other coping strategies. Again the size of the indicator illustrates the frequency and extent to which the participant uses the strategy according to the data.

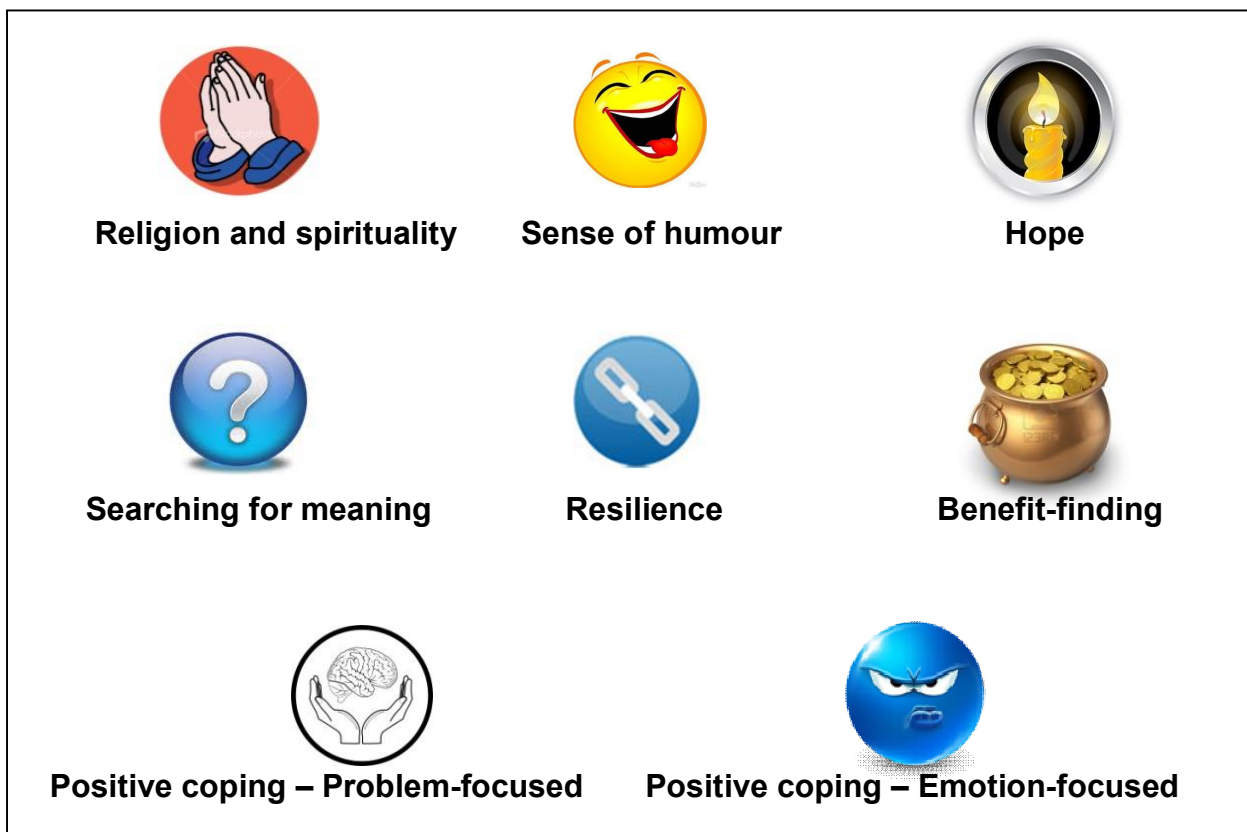


Figure 6: Keys

5.3.2 Method of identifying themes

The following examples of extracts are illustrative of the themes that were identified from data that were rich in detail.

5.3.2.1 Examples indicative of benefit-finding from TM

Anne: *“TM is part of my life – it has, in fact, enriched my life, by allowing me to focus on the many positive aspects of my life. I have life, I have a good life – and I am eternally grateful for that. My life experiences have helped to shape my positive mindset.”*

Eric: *“I am a much better person after I became ill with TM. I used to be impatient and intolerant before I became ill.”*

5.3.2.2 Examples indicative of hope

Anne: *“The reality of life is that every single one of us will have to face difficult challenges throughout our lives. The onus lies on us to realise and understand that every challenge can teach us a valuable lesson. I know that it is my attitude towards life that will ultimately determine the quality of my life.”*

Drew: *“One should hold onto one’s dreams and faith. If one does not do so, it could lead to suicide, so always keep faith. Believe in yourself – not in other people. Sometimes life turns its back on me but I firmly believe that the sun will always shine on me.”*

Eric: *“One should always hope. I received special shoes and from now on I will walk more comfortable. The orthopaedic surgeon only wants to operate in five years’ time and by that time I will not need that muscle anymore!”*

5.3.2.3 Examples indicative of inner strength and religious connection

Anne: *“I believe that inner strength is a unique human quality that can be found within everyone. It’s a strength that forms part of the core of any human being and is a force that prevails, regardless of how bleak the situation might appear to be! I thank God that I am aware of the power of my inner strength and that I have been able to use it in a positive manner.”*

Drew: *“I received the courage and determination from the Lord because I can feel that there is a continuous voice inside me that pulls me forward.”*

Eric: *“The one prayer after another to God kept coming to my mind. At one stage I could not even brush my teeth. I was not able to do anything. I just lay there and spent my time with Jesus.”*

5.3.3 Anne

5.3.3.1 Biographical information of Anne

Anne is a 26 year old female, diagnosed with TM in 1999 after paralysis developed at the T8 level, with excruciating back ache and stomach pains (see annexure C). Her health had its ups and downs for more than ten years. Various intestinal diseases developed affecting her physical well-being. She was also diagnosed with antiphospholipid syndrome (an autoimmune disease where abnormal proteins called antiphospholipid auto-antibodies are present in the blood. It causes blood to flow improperly and can lead to dangerous clotting in arteries) and osteoarthritis (a degenerative arthritis is a joint disease caused by cartilage loss in a joint.)

Anne grew up in a children's home where she at an early age had to learn not only how to fend for herself, but also to understand that life is about facing challenges head-on and using such challenges in a positive manner. She has a steady job and during her illness, her fiancée and his family, close friends and colleagues showered her with support and love.

5.3.3.2 Clustering of themes for Anne

She maintains a *positive outlook* towards self and life, not allowing her soul or spirit to be affected. Hardship throughout life gave her a positive mindset, which brought resilience, spiritual and inner strength: (“It affects my body and limits my physical ability, but in no way has it affected or limited my soul or spirit. It has, in fact,

enriched my life, by allowing me to focus on the many positive aspects of my life. I have life, I have a good life . and I am eternally grateful for that.+)

She has *resilience and a positive mindset* by learning through hardship: ("I grew up in a children's home where I had to learn at an early age not only how to fend for myself, but also to understand that life is about facing challenges head-on and using such challenges in a positive manner+.)

She has *hope and optimism* as well as in her outreach to others, an empathic understanding especially of people with disabilities (% The current structure of the [building of the provincial] legislature makes it impossible for the disabled and extremely difficult for the elderly, to access the public galleries and venues for committee meetings. I circulated the petition to many organisations for the disabled and was completely overwhelmed with the support it received. Every single signature penned on the petition contributed to creating a sense of awareness and the [provincial] legislature has since started obtaining quotations to have the building revamped. So, every little bit we contribute, no matter how small, can be the catalyst for bringing about changeõ +)

Social support helps her: ("õ During my illness, my fiancée and his family, my close friends and colleagues showered me with incredible support and love.+)

Political involvement and active promotion of the plight and rights of people with disabilities give meaning to life with the aim of improving other peoplesqlives.(% I recently started a petition against my employer, the provincial legislature, to make the building more accessible as there are three levels with no lift facilities or wheelchair ramps.+)

She displays *self assertion*: ("Last year while in the hospital, I made the following four promises to myself: (a) that I would never give up during the physiotherapy sessions, (b) that I would go back to work if I recovered, (c) that I would get my driver's license and (d) that I would create awareness about TM and be there for others who have TM.+)

She has an *empathetic understanding* of others: ("There is so much that we can do if we commit ourselves to becoming actively involved and stand together to make a concrete difference in someone else's life.+)")

She has a *religious connection* and uses *religious support*: ("I have by the grace of God managed to do the first three and am currently working on establishing a support group in South Africa.+)"); (%thank God that I am aware of the power of my inner strength and that I have been able to use it in a positive manner.+)"); (%there are often days when depression rears its ugly head, yet by the grace of God I sustain enough strength to prevent depression overshadowing my life.")

She displays *spiritual strength*: ("It affects my body and limits my physical ability, but in no way has it affected or limited my soul or spirit.+)")

5.3.3.3 Summarised coping strategies of Anne

She seems to deal with her illness and more so with her recovery in a very positive and constructive way. Feelings of depression are countered by her belief in God (religion).

A positive outlook and a philosophy of self-determination and a positive mindset, coupled to experience of hardship, characterises her as a person with intellectual and rational abilities.

5.3.3.4 Coping graphic for Anne

The clustered themes of Anne, compared with the seven constructs (Snyder & Lopez, 2002) of positive psychology (seen as %the voice of the people versus the voice of theory+) are presented in Figure 7.

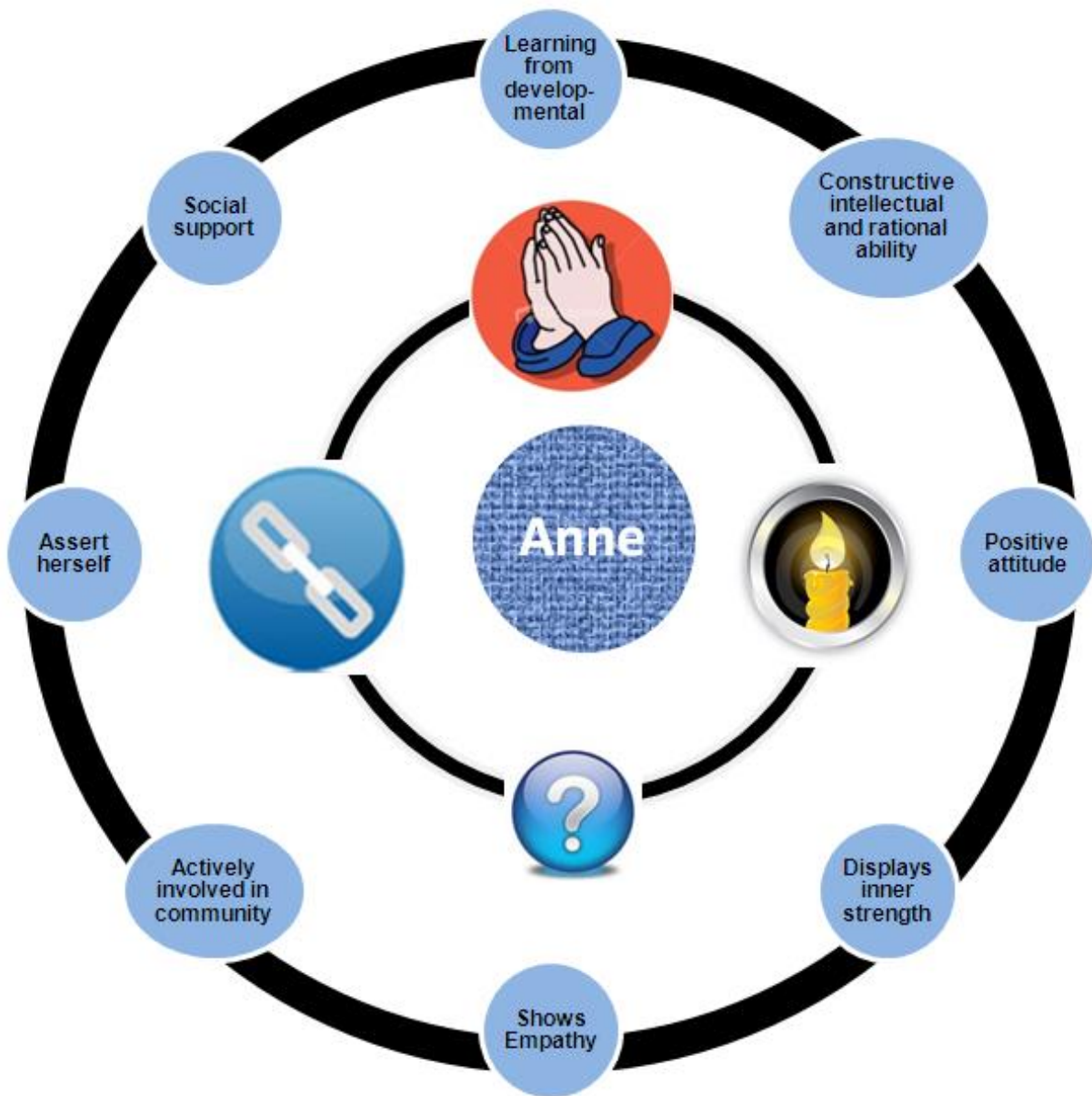


Figure 7: Coping graphic for Anne

Anne's coping graphic shows that she makes use of four of the seven established coping strategies, namely *religion and spirituality*, *resilience*, *hope* and *search for meaning*. She uses the four strategies with different frequencies or intensities as indicated by the size of the relevant symbols. From the clustering of themes the research team found that, in addition to these coping strategies, she makes use of eight more. These additional coping strategies, not from the seven established constructs, are indicated by the eight *ball-and-descriptor* symbols on the outer circle. The short printed descriptors indicate the nature of these additional strategies.

5.3.4 Bert

5.3.4.1 *Biographical information of Bert*

Bert is fifty six years old (see annexure D). He is a farmer on an estate of four farms. He reveals little about his background, but he writes that he received a "good" upbringing. He says that his parents laid the foundations for his life ~~on~~ on their knees+ (a common local reference to prayer). He talks about the symbolic house of his life which is based on his religious faith and his communication with his parents. He views life values (respect and self-respect) as the result of his upbringing. He is focused on his faith and God and maintains a humanitarian predisposition towards other people. Bert is married and has children. He was a water polo player before he became ill with TM. He loves all kinds of sport and also used to be a scuba diver and cyclist. He has hobbies such as woodwork and leather craft.

5.3.4.2 *Clustering of themes for Bert*

Rationalising and intellectualising seem to be means of communication for Bert. His inner strength is utilised for problem solving: ("There are at least ten solutions to each problem. Every problem is a challenge and I thrive on it+).

He utilises strong *religious and metaphoric* ways of relating to be positive and self-determined: ("Everything is about the glorification of God. Everything and everyone exist in order to spread the word of His magnificence. Without childlike faith and trust, we are exposed to fear and doubt; to Satan's dividing wall of betrayal+).

He disregards his self-interest while viewing God as omnipotent and important for his existence: (%o.. because each of us is made for His purpose, because it is not about ourselves+).

He has a *sense of humour*, albeit offered intellectually and in metaphorical terms. He uses an intriguing expression that is hard to translate: ("Ek is baie jammer ek skryf soos harmansdrup in die winter, maar ek het net te veel ysters in die vuur ... ")

This is an (unnecessary) apology for not replying in writing swiftly, but phrased in a round-about way; something akin to: %am very sorry I write like *harmansdrup* (a thick and sticky form of Haarlemensis, an old Dutch medicinal oil that takes long to form a droplet) in the winter (when it drips even slower), but I have just too many irons in the fire (things to attend to). He has many matters that demand his attention and keep him busy. These things distract him from his illness and give meaning to his life.

Physical and medical self knowledge of the functions of his body are important to him; it seems to help in the healing process. Professional medical support counters any self pity that might have arisen and assist him to fight the illness aggressively. Knowledge about TM gives him a sense of control regarding the neurological changes in his body: ("My attitude was, therefore, to tackle this thing as aggressively as possible and to conquer it as soon as possible+).

He *searches for meaning* through intellectualising his illness as well as by seeking the word of God (religion) as power motivation: ("There is a fountain full of knowledge and information that longs for you to put out your hand and delve in it+); (%Find information about the topic ò take stock of all your information or knowledge, analyse it critically and then make a decision on how to handle and beat the situation+). He makes use of problem-based coping since he analyses problems, make certain decisions and do something about them.

He specifically highlights *interpersonal involvement* indicating that he shows respect to other people and values self-respect: ("In these times I learnt about respect and self-respect+).

5.3.4.3 Summarised coping strategies of Bert

From the vantage point of the researcher, Bert seems to be divorced from his true inner self and his feelings in his communication about TM. It was consequently not easy to get to know Bert as a person in the relative limelight (albeit *in cognito*) of a research project. His language, though spoken earnestly, presents an intellectual

veil of metaphors, religious and philosophical quotes aimed at proving his positiveness towards life and his ways of coping: ("The bricks from the Word, the walls of my life are built with them; the plaster of education cemented these bricks unto the foundations of my life".)

Interpersonal involvement and mutual respect is important to Bert. Hope and meaning are aspects of his religious belief system; his self-motivation is described as beyond himself: he has to rely on God alone.

5.3.4.4 Coping graphic for Bert

The clustered themes of Bert, compared with the seven constructs are presented in Figure 8. This coping graphic follows the same pattern as the one for Anne that is shown and described in sub-paragraph 5.3.3.4 above.

Bert's coping graphic shows that he makes use of six of the seven established coping strategies, namely *religion and spirituality*, *humour*, *hope*, *problem-focused positive coping*, and *search for meaning* and *resilience*. He uses *religion and spirituality* more often than other strategies, as indicated by the larger logo. The clustering of themes indicated that he also uses five additional coping strategies, not from the seven established constructs. These are indicated by the eight *lit up* (light blue) *ball-and-descriptor* symbols on the outer circle. The short printed descriptors indicate the nature of these additional strategies. A few outer logos remain greyed out, as no more really apparent additional coping strategies are, according to the clustered themes, used by Bert.

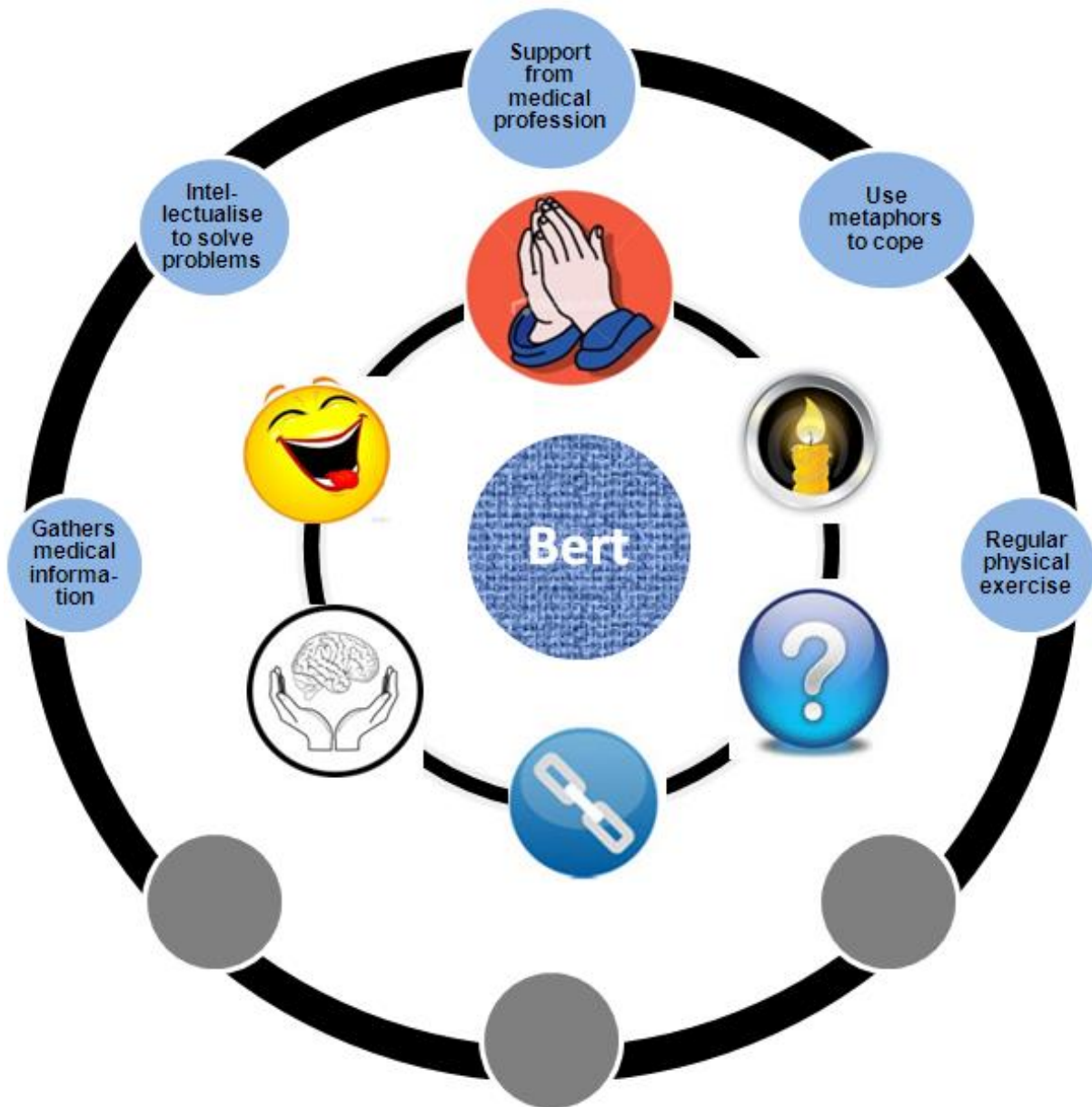


Figure 8: Coping graphic for Bert

5.3.5 Cate

5.3.5.1 *Biographical information of Cate*

She gives little personal information and particulars of herself (see annexure E). She is 62 years old. She is married to a "kind man". She has had TM for the past seventeen years. She stays busy in one way or another (usually with needle work)

and uses this as a coping strategy. She sketches herself as a lonely and private person and as someone that applies self-control in dealing with the effects and management of TM.

5.3.5.2 Clustering of themes for Cate

She displays *anger/aggression* towards the disease: ("I am aggressive to the disease+).

She has quite an amount of *repression/resistance* to the disease: ("You can't see the disease . no bruises. I kept quiet. Talking about it makes me depressed+).

Her personal limitations result in her *social isolation*: ("I feel lonely . nobody knows the diseaseō I can only stand or lie down; I cannot sit+).

She *finds meaning* by staying busy with needle work: ("I go to all my meetings with my sewing machine.+)

She makes use of *cognitive restructuring*: ("Other people are worse off than me. This is a small problem. I am big.+)

She uses *denial and distraction* as a coping strategy: ("I bury the weaknesses. If I acknowledge the disease, it brings me down. I ignore it now. I don't talk about it ... if I ignore it, I am in control. I think of other things+).

She displays *inner strength* and rejection of weakness in others: ("Bed is for sick (ill) people. I won't be weak.... adapt or die . I will not die+).

She has a *positive attitude*: ("ō so many things in life to learn. I focus on challenges.+)

Self-assertion and *self-preservation*: ("I like putting make-up on a scar. I don't ask favoursō I go to meetings with my sewing machine.+)

She *finds benefit* from TM: (I value life more. Now I value what I can do→).

She is *optimistic, independent* and full of *hope*: ("My husband raised all the tables in our house because I cannot sit. Now we both stand and eat. Fortunately, I can still walk→).

She *does not display self-pity*. She appears strong: ("Don't complain to me. I have no sympathy with poor people.→)

She has *no sympathy with people who feel sorry for themselves*. She manages her own emotions by fighting her moments of despair. She feels that she needs to be strong to fight her own problems: ("I respect people more who are really ill. I disrespect [complaining] people who are not ill.→)

She has a *positive attitude*: ("I have so many things in life to learn. I focus on challenges→).

She *finds meaning* by staying busy with needle work.

5.3.5.3 Summarised coping strategies of Cate

Cate seems to suppress negative thoughts about the effects of her illness and resists communication about it as well. She believes in self-control and willpower as means of survival: ("I can beat it I will fight I adapt or die . I will not die→).

She is aggressive towards the disease: ("If I acknowledge the disease, it brings me down. I ignore it now.") Underlying feelings of depression and helplessness are balanced with a feeling of optimism and a state of independence.

A positive attitude (no self-pity) and self-employment give her hope and belief in her survival.

Her needle work assists her to find meaning in her life.

5.3.5.4 Coping graphic for Cate

The clustered themes of Cate compared with the seven constructs are presented in Figure 9. This coping graphic follows the same pattern as those for Anne and Bert that are shown and described in sub-paragraphs 5.3.3.4 and 5.3.4.4 above. Cate's coping graphic shows that she makes use of *hope*, *benefit-finding*, *search for meaning*, *resilience* and humour. Like Anne, Cate uses eight additional coping strategies as indicated by the eight *ball-and-descriptor* symbols on the outer circle. The short printed descriptors indicate the nature of these additional strategies.

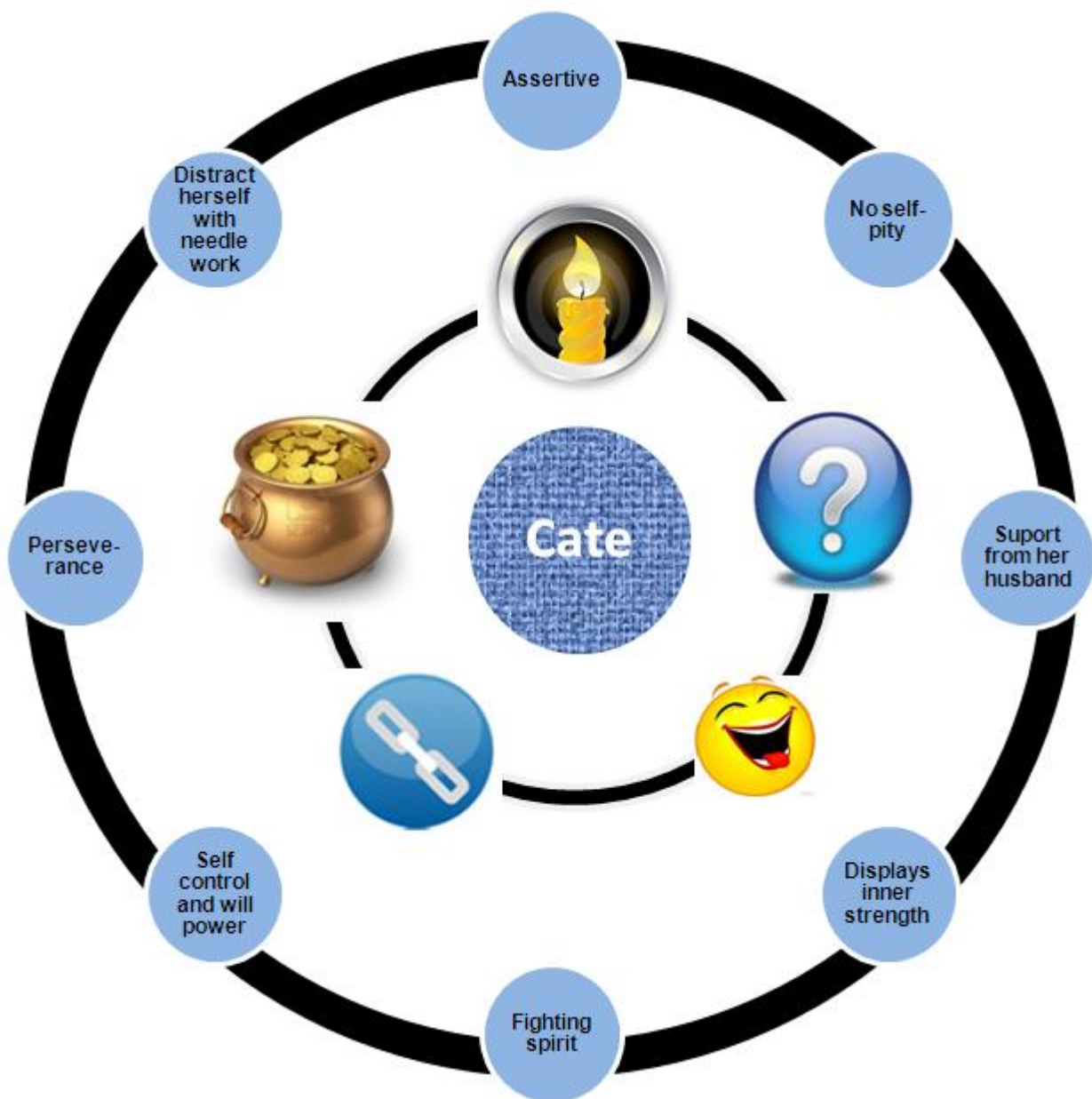


Figure 9: Coping graphic for Cate

5.3.6 Drew

5.3.6.1 *Biographical information of Drew*

Drew is a forty nine year old woman (see annexure F). Approximately seven years ago, she felt a sudden pain in her chest and had no strength in her hands. A MRI scan, as part of a medical investigation, revealed she had a virus in her spinal cord, between the T1 and T2 vertebrae. Medication brought some relief to pain in her fingers, but she is still physically dependent and disabled. A physiotherapist taught her to walk with a walking ring, which decreased the measure of paralyses in her body and especially in her legs. The physiotherapy improves her physical power. At home she is dependent on a wheelchair as well as on her husband's emotional and physical assistance. She experiences support from her family, friends and even from complete strangers. Religion and religiosity plays a key role in her general disposition and is a great motivator to her. Currently the paralysis in her legs and right hand make movement extremely challenging. Despite her physical disability she is determined to carry on with the bookkeeping job she does for her husband. Her husband's involvement indicates that they have a close relationship and that religion is very important to both of them.

5.3.6.2 *Clustering of themes for Drew*

Drew has a strong *religious connection* in her Christian belief system which emphasises prayer: ("The one prayer after the other. Through all the pain I call out to the Lord. I just continue praying and the peace engulfs me... with the hand of the Lord upon me ... I received the power and perseverance from the Lord.") This is echoed by her husband: ("Here I again realised what a wonderful God we all worship. When they visited her, they also came to speak to me and in their prayers they entrusted me to Jesus too. The staff supported me and spoke to me about Jesus. It was a fantastic experience that strengthened me in my faith").

She appreciates the *social support* of her friends and husband: ("Petro and Trudie are the most wonderful dear people. But thanks to my wonderful husband that always keeps me positive... Family, friends and strangers supported me+).

A good *sense of humour* and small interpersonal interventions (of husband) assist her towards a positive attitude: ("I tried to scrape the crumbs from a plate, but what a joke . Jackie had to fish the plate from the rubbish bin; it fell out of my hand+).

She displays *resilience* through her religious beliefs, her self-determination and her attitude towards her challenges: ("That is how one adapts to one's circumstances; I thank God for the wonderful husband I received. He has always helped me and kept me positive+).

She finds *meaning in her life* because she works full-time and is, therefore, still intellectually active (%do all our bookkeeping personally+). She also finds meaning by keeping herself busy: (%When I listen to my Christian CDs or to the sermons that I taped because I am involved with cassette ministries+).

She *finds benefit* and is grateful because she compares herself to other TM patients who are worse off: ("I am grateful because many people with TM cannot walk at all+).

She underplays the emotional effects of TM, e.g.: frustration and anger towards medical staff: (%and while the physio[therapist] was so insensitive, my husband walked in and he was very unhappy about the treatmentõ but the matron later came to apologise on her behalf+).

5.3.6.3 Summarised coping strategies of Drew

Religion and specifically Christian connections give her resilience and meaning in her life. She values spiritual health above physical health. She, regardless of her illness, accepts challenges (working as bookkeeper), therefore, is intellectually active too.

She finds *meaning in her life* when she spends quality %me+time in her study during the mornings. Then she listens to music and tapes sermons on audio cassettes. She seems to transcend to something bigger than herself and also finds meaning in serving other people with her spiritual cassettes. (%When I listen to my Christian CDs or to the sermons that I taped because I am involved with cassette ministries+).

She acknowledges the support of others, family, friends and is grateful for the professional assistance of physiotherapists: ("Rina ... my new physio ... took me to the swimming pool and it was so pleasant"). Resilience, a positive outlook, self determination, hope and trust are important factors for coping with TM.

Cognitive restructuring - she sees the benefits of still being able to walk.

She has a good sense of humour and gives examples of funny occurrences where her hands did not function properly causing small accidents in and around the house that make her laugh.

5.3.6.4 Coping graphic for Drew

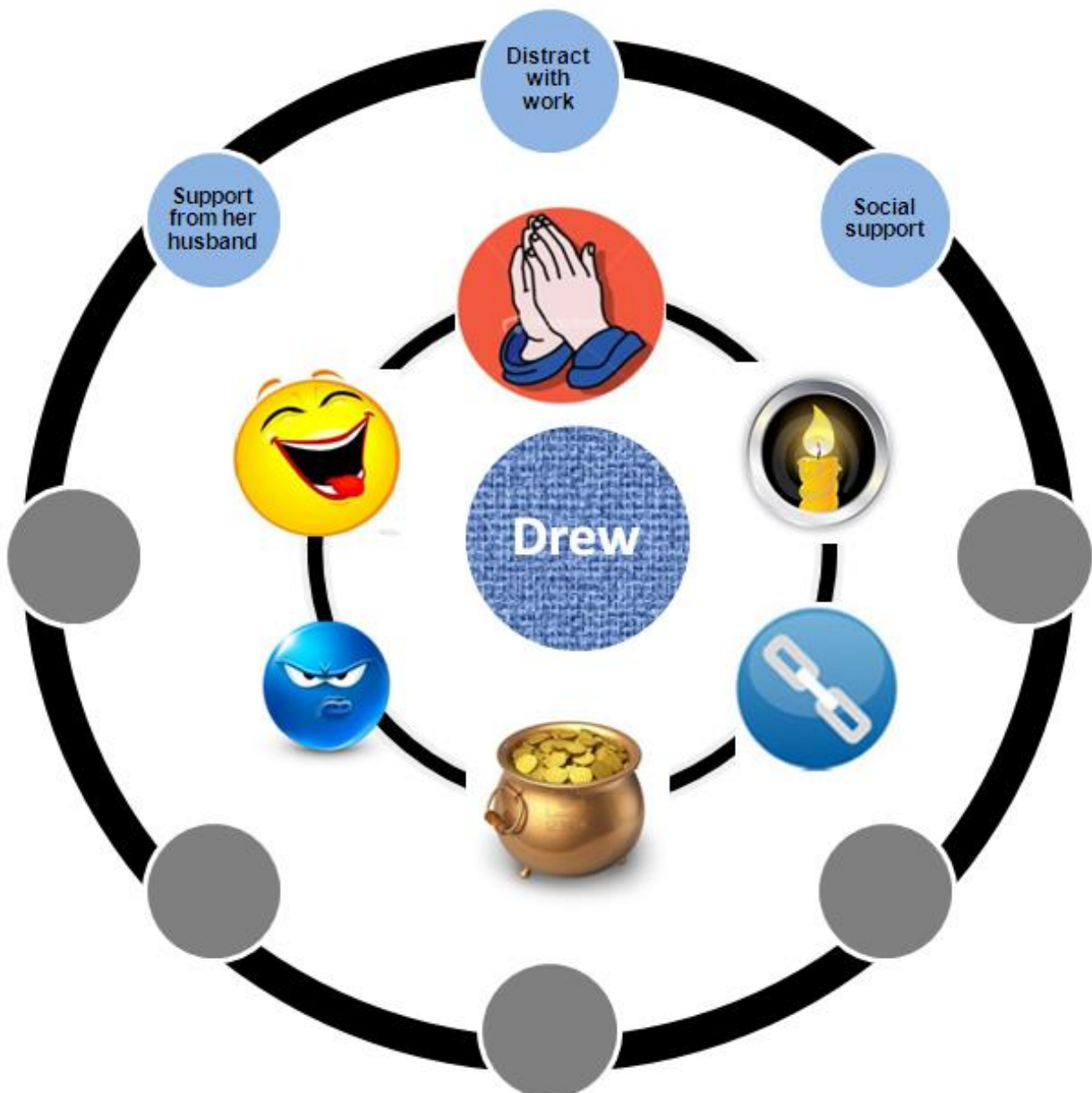


Figure 10: Coping graphic for Drew

The clustered themes of Drew, compared with the seven constructs are presented in Figure 10. This coping graphic follows the same pattern as those for Anne, Bert and Cate that are shown and described above.

Of the seven established coping strategies, the coping graphic shows that Drew uses *religion and spirituality*, *humour* and *resilience* more than *hope*, *emotion based positive coping* and *benefit-finding*. She uses three additional coping strategies which are indicated by the lettering on the *ball-and-descriptor* symbols on the outer circle.

5.3.7 Eric

5.3.7.1 Biographical information of Eric

Eric is currently fifty three years old (see annexure O). He describes his childhood as problematic. He was born in the Eastern Cape and grew up in a village some distance from his place of birth. At the age of fifteen things went wrong and he was instructed to leave his parents house. He fled to a friend's home and the friend's parents accepted him as a part of their family. After he completed school, he joined the army, something he is still proud of. He later became involved in mining. He is married and his wife is currently his care-giver. He has a daughter.

At school, he showed talent for sports, specifically in the areas of boxing and rugby. In his adulthood, he continued playing rugby. For five years, from 1997 until 2001, he took part in the famous Comrades marathon . a long distance endurance race of approximately ninety kilometres.

In 2002, Eric became ill with TM. The first symptom of TM was a sudden sharp pain in his back. Physicians were not able to diagnose Eric's condition correctly. Today he is wheelchair bound and has continuous bouts of pain. The disease had a negative effect on Eric's ability to work, as he was later retrenched from his job at the

mine. Fortunately, he was offered work as a handyman who fixes wheelchairs and other equipment for disabled people.

Eric sent two e-mails six months apart. The first letter is written in English and the second letter is written in Afrikaans. The first letter mainly contains the factual information of the medical course of his initial symptoms and experiences of TM. The second letter focuses more on his emotional and coping responses to TM over the years. The themes below emerged from these letters.

5.3.7.2 Clustering of themes for Eric

It is evident that he experienced emotional and physical shock in becoming disabled. His athletic abilities and independence had to make way for a different self, a dependant one, relying on others: ("Then transverse myelitis struck me down and still affects me today.+))

Pain brought feelings of despondency, helplessness, depression and despair as well as anxiety of not-knowing (in the early phases of check-ups). These feelings were coupled with interpersonal bluntness towards the seemingly cold care+ attitude of medical staff, which left him in a state of helplessness, even hopelessness: ("At 12 pm that night I went back to the hospital for the third time. By then the pain was excruciating ò I went to the bathroom but the urine did not take its natural path ò it didn't come out. My legs felt weak ò I walked three steps and then I fell. That was the last time that I could walk.+))

He overcame his earlier losses: (%At the age of fifteen things went wrong and I was instructed to leave my parents' house. I fled to a friend's home and his parents accepted me as part of their family. When it was time I went to the army, I joined one of the army's elite battalions.+)) He recouped his family-life by forming a new family with his wife and daughter. This made him a self-assertive family man before he became disabled. TM causes him to experience major losses again. He lost his ability to walk and he requires a urostomy bag. (*Urostomy* is a surgical procedure that diverts urine from the kidneys and urethras into a specially created stoma. A *urostomy* bag is stuck onto your abdomen where it collects urine.)

His disability came as a shock because he explains that it %struck him down+ and affected his whole life. Immense bodily changes, loss of movement and general functionality changed his life and his attitude towards life. Regarding the last mentioned, he believes that TM made him a better person, changed him from a moody person into a more patient and aware person. He *found benefit* from the disease: ("... The job opportunity that the head office had available was to help prepare wheelchairs and to help paraplegics with certain resources ÷ I used to be short tempered but now I have a lot of patience.+)

He has a *positive attitude*, a *sense of humour* and is at peace with his illness: ("At work, we are three employees in wheelchairs and we gave ourselves a funny . or strange . name"). The humour in the name they used ("*die Lamgatbende*") gets lost in translation as the name, as it is constructed, captures all of the earthiness, empathy and slight obscenity of the names *the Paralysed Gang*, *the Lazy Loafers* and *the Lambe-arsed-Squad*.

He finds *religious meaning*, together with the grace of God and it made him determined to overcome a negative attitude and destructive emotions such as depression and hopelessness: ("God promises us that He will never bring events into our lives that we cannot overcome.+)

He *rejects sympathy* and pity and the %long care+attitude of people which provokes anger. He is angry because people are ignorant and reject people with disabilities: ("One thing which I neither believe in nor hand out is sympathy and self-pity.+)

He finds *meaning in life* because he becomes useful by advocating the plight of people with disabilities and uses his disability to the advantage of other disabled people (e.g. repairing wheelchairs). He also participates in spreading of knowledge about TM: ("[I can help] paraplegics with certain resources ÷ I am very glad to say I am helping handicapped people by repairing wheelchairs.+)

He appreciates all his *social support* and he *finds meaning and benefit* in his illness and in his marriage: ("TM made me a better person."); (My family and my wife are the best. I will not exchange her for anything in the world.)

He comes across as realistic about life, which in times of despondency is soothed with his sense of humour, caring love, trust in self and others: ("You can probably see that I remain positive. It works for me and I believe it can also work for someone else. I hope you can use this letter in some way or another.")

5.3.7.3 Summarised coping strategies of Eric

He is *resilient*, a characteristic which he displayed even before he became disabled. For him resilience is important to overcome the pain, physical and emotional handicaps of TM. He makes use of practical problem solving: ("I do cross that bridge when I get there"); (The circumstances in which you find yourself ... pick up the pieces and continue with your life, take those pieces and turn them into something positive).

He balances his emotional turmoil with being *active in the community*, being self-employed and useful, seeking no sympathy or pity. He feels proud of his physical and mental achievements that he applies for the needs of people with disabilities: (I like doing my job (fixing and constructing wheelchairs) for the pleasure it provides me and not for the money I make out of it.)

He is assertive, possibly because of an acceptance of a different *new* self and assumingly *at peace* with the illness.

A *positive attitude* provides *hope* and assists him to *find meaning* in his life despite his physical limitations: ("As family we are closer to each other. My wife is the best; I will not exchange her for anything in the world.")

Sympathy and pity is rejected and replaced with *humour* and *hope* and a *caring attitude* towards those who really understand and care for those with disabilities. He is disillusioned with those who reject disabled people and this leaves him distrustful towards people.

He became an advocate for the rights of people with disabilities. *Resilience* and *assertiveness* made him a spokesperson for people who are disabled. He becomes a motivational speaker in this regard.

He has a *philosophy of coping* which allowed him to grow personally to appreciate the closeness of family.

The *social support* that he receives from his family leads to an interpersonal appreciation of his family. His ability to still have dreams in life, instils *hope*. These factors add value to his ability to cope with TM: ("We should never doubt and stop believing in our dreams+); (%As a family... we always support each other+).

5.3.7.4 Coping graphic for Eric

The clustered themes of Eric, compared with the seven constructs are presented in Figure 11.

Following the, by now, familiar pattern described for the other four participants above, it can be seen that Eric uses *religion and spirituality, humour, hope, problem-focused positive coping, search for meaning, resilience* and seven coping strategies that are not among the seven established constructs.

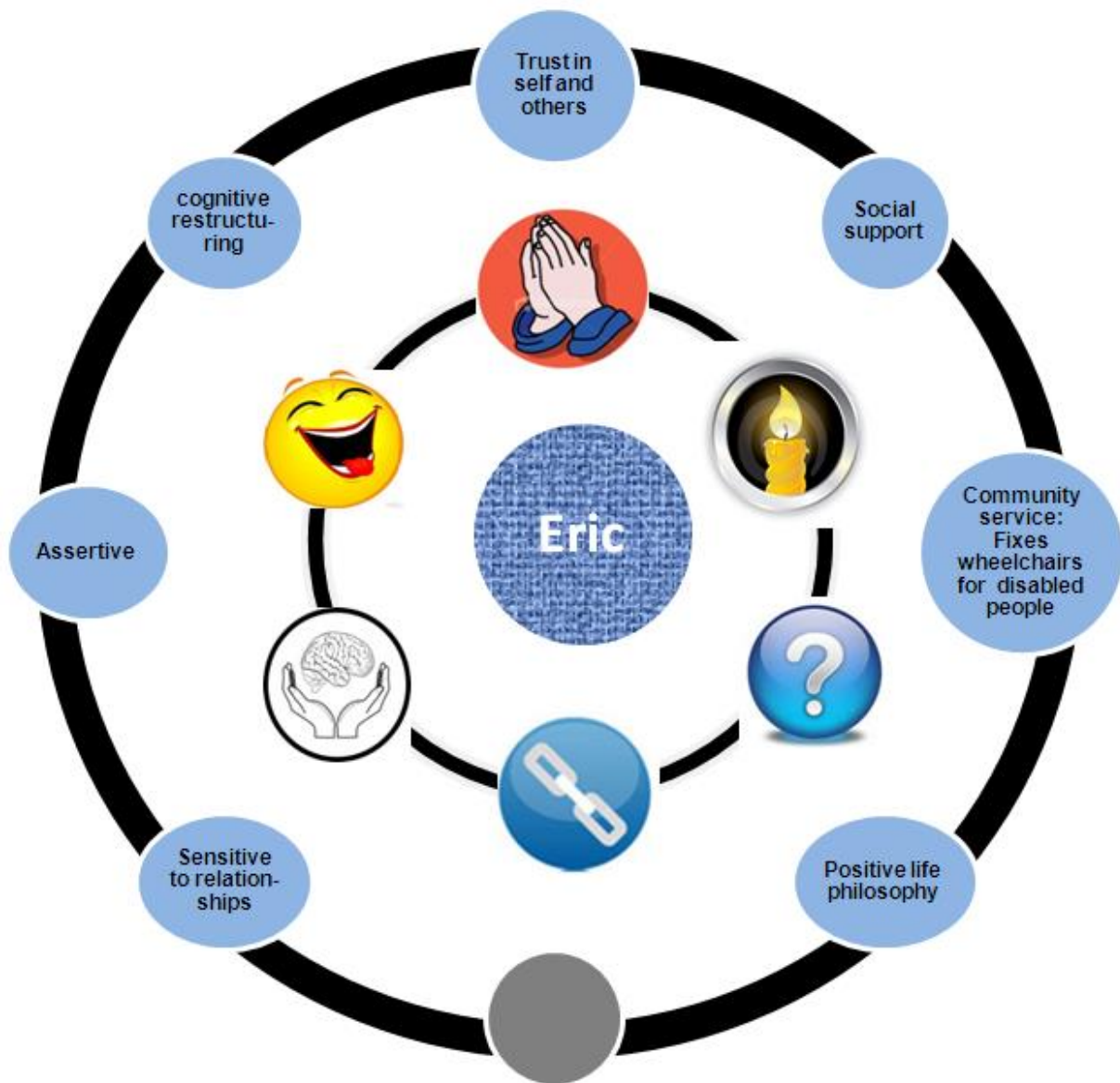


Figure 11: Coping graphic for Eric

5.4 Integration of all five participants' coping strategies

Resilience in support of self determination seems to be a strong factor regarding the maintenance of mental health in the midst of all the suffering caused by a neurological disease such as TM. A side effect that arises from this is that a positive attitude seems to develop from the dynamic process of humour combined with constructive interpersonal dealings with significant others.

A new self seems to develop which means that another appreciated meaning is attached to life and existence, contributing to a positive philosophy of life. In practical terms it seems that the original, pre-TM self is left behind and the post-TM self, including all the new emotions and altered behaviour that is brought about by this disease, is accepted as the new self. Self control and willpower are two important factors to maintain assertiveness and self preservation.

It seems that experiences of hardship in life, gathered during childhood, help patients to face and overcome the painful realities of a life with TM. Religion and inner spiritual strength are fairly strong support mechanisms. It seems that where physical and accompanied emotional strengths fail, metaphysical ideas such as religion, spiritual attitudes and communication with God via prayer, feature strongly.

Besides religious and spiritual behaviour, intellectual and rational thoughts are also emphasised. Intellectual thinking contributes to a preparedness to engage in active participation in career orientation, social gatherings and causes bigger than oneself, such as promoting and protecting the rights of disabled people. Their active search to obtain information about TM provides a sense of control.

Relationships with significant others, such as family members and friends seem to be important to minimise personal and social isolation. Interpersonal feedback plays a significant role in these relationships. It seems to also bring a form of hope and help in self acceptance.

Almost all the narratives contain the theme of sense of humour. Humour is used on both interpersonal and intra personal level. Real humour is characterised by the ability to laugh at oneself and this becomes a form of second-order thinking which gives new meaning to what is actually presently happening.

Care-givers (spouses, family members, friends), especially the medical staff and related social professions are very important to maintain physical ease and mental

health. Even the so-called negative traits seem to play an important role in the coping process. Intellectualisation and cognitive restructuring do not always take the realities of TM into account but are successfully utilised to maintain mental health.

Similar to intellectualisation and rationalisation is the issue of denial. Denial, as viewed in psychological terms, is often seen as negative and even harmful to a person's mental health. Emphasis is rather placed on open and honest communication, recognition of feelings and self congruence. However, denial has a positive effect in specific contexts of disruption and emotional turmoil. It gives one the opportunity to adapt to the inevitable situation of a broken body and mind over time. Humour could be a form of denial too, laughing with a tear. This means that real sorrow can hide behind humour.

Social isolation from the broader community seems to have a positive value when the hurt and embarrassing moments affect a patient's self-worth. It offers a valuable silence away from the intrusion of superficial interaction with people who do not understand the scope of this disease. Aggression is felt toward people who do not truly understand disability. Conversely, social cohesion is built amongst people who are disabled and amongst them and the inner circle that empathise with them.

5.5 Chapter conclusion

This chapter discusses the data of each participant. Brief information is given about each participant and about his or her physical, emotional and interpersonal situation in dealing with TM. Clustered themes based on the emerging themes are derived. The emerging themes as interpreted from the original data are attached as appendices (K, L, M, N and O). Summarised descriptions of each of the five participants' coping strategies with TM follow.

From the clustered themes of the participants' interpretations, rational deductions are presented. These are then compared with the seven constructs (Snyder & Lopez, 2002) of positive psychology (the voice of theory) where new ideas emerge. The

results are documented and explained in Coping Graphics for each of the five participants (Figure 7 to Figure 11).

From the summarised descriptions as well as from the voices of the people+ and from the proverbial voice of the theory+ a model for coping will be designed. This model as a main objective of the study is presented in the next chapter.

Chapter 6

Towards a coping model for the well-being of patients with TM

6.1 Introduction

The development of a coping model for the well-being of patients with TM could, from a psychological point of view, be regarded as challenging and may even be considered presumptuous. It is nevertheless important for people suffering from TM. These patients aim to attain what they perceive to be natural for (healthy) people. They must therefore find ways to cope and deal with their lives, despite the daily exposure to illness, discomfort and pain. Coping, the ability to manage individually as well as socially is vital to one's existence, self-image and social self. Coping is attached to self-respect, motivation, the will to live and the ability to be interpersonally at ease with others, be it family, friends, colleagues or other associates.

The model under development consists of a set of coping strategies. Depending on each TM patient's unique context, different psychological strategies from the set can be used with varying frequencies and intensities during the course of the illness.

The objective of this study was to develop a coping model for the well-being of patients with TM. In chapter 2 it has been shown that preceding models for the management and/or alleviation of pain and coping with stress have already been proposed. Existing psychological models and methods are used to assist people in dealing with chronic pain. The use of such models is an attempt to ease illness and promote psychological and physical well-being.

In chapter 2 it was also established that adequate pain management procedures, being medical, psychological or both, should be an essential part of the treatment of chronic diseases. Medication and alternative methods of pain management, be it psychotherapy, hypnosis, meditation or others, could assist towards pain management and the improving of the lives of the TM patient. Because chronic pain justifies a coping model of its own, it will not be emphasised in the proposed TM coping model in this study.

The development of a coping model depends on a variety of factors, which makes it complex. It cannot be rigidly applied in the same way to all patients with chronic diseases. Even in the case of TM, the stage of the disease, the severity, the symptoms, treatment procedures, exposure to medical tests and medical equipment affect the well-being of the patient. Additionally, the life experience and personality of the patient, as well as the nature of the psychological and social environment, result in different requirements for coping models or strategies for efficient treatment.

With this in mind, the present proposal of a coping model should be regarded as a guideline to assist patients or for the application by care-givers of patients.

The proposed model is based on four argumental pillars, namely:

- existing coping models (chapter 2),
- the *voice of theory* (chapter 3, on literature),
- *observations* and *interpretations* of the research team (including the researcher and two clinical psychologists, see chapter 4) and
- the *voice of the people*, i.e. the needs of the participants (as expressed in their data and in the results, see chapter 5),

As outlined in chapter 2, the onset and development of TM is often a severe crisis, due to the typical sudden and unexpected appearance of the disease. A health crisis precipitates a turning point in an individual's life, especially when ill health progresses into a chronic disease or disability. The intense confrontation with a serious physical disease, the extended treatment, the uncertainty and the intense personal misery, have a lasting and deep impact.

Relative adaptive tasks and coping skills as well as determinants of adaptive coping with TM and disability are important to manage the crisis and to promote psychosocial recovery. It, more often than not, places a heavy burden on the patient and his or her family or care-givers. Chronic illness such as TM does not only affect the person physically, it also has severe consequences emotionally, mentally and socially. A chronically ill person can be psychologically vulnerable. Sick people's personality structure, the emotional reaction of family, the behaviour of the physician, the physician's staff, the hospital staff and the patient's friends all affect his or her vulnerability. Holland and Ward (1996) also believe that anxiety regarding the perception of the degree of the illness affects the patient's present and future ability to work and his or her financial security.

Schaefer and Moos (1998) state that the traumatic aspect of a clinical infectious disease cannot be denied. Yet, individuals often emerge from the onset of a disease such as TM with new coping skills, closer relationships with family and friends, broader priorities and a richer appreciation of life. Adaptive coping is central to psychological growth in the context of health crises. Positive feedback from successful coping experiences strengthens resources under adaptive challenge. Resilience develops from confronting stressful experiences and coping with them effectively; novel crisis situations promote new coping skills, which can lead to new personal and social resources. Some TM patients may need assistance to adapt and experience personal growth from the negative experiences of their illness.

When people are chronically ill and often in severe pain, how can they cope with it?

The study found that people need to be loved and needed; they have a need for inner sense of harmony and well-being, for a sense of personal freedom and liberation and an opportunity for growth and change. Interpersonally, subjects noted the importance of unconditional acceptance and understanding from others, the experience of sharing and trust, authentic and deep friendship and being able to give and nurture, as well as receive nurture. Finally, subjects repeated that such intimacy at times lead to feelings of transcendence, of being one with the world. The last need, which is a characteristic of a fully functioning person, is to reach transcendence through relationships. The interpersonal relationships of a chronically ill patient can therefore contribute to his or her psychological well-being.

6.2 Constructing TM coping model

6.2.1 Proposed coping model

The key question in creating a coping model for TM patients was: ~~why~~hence the strength?+

In an attempt to organise the TM coping model, coping constructs that emerged from the clustered themes and the literature study (chapter 3) are graphically represented in rings. The network of key coping strategies is presented as follows:

- An inner circle depicts coping strategies that emerged from the clustered themes and which also form part of the seven established theoretical constructs discussed in this study. They are:
 - Sense of humour,
 - religion and spirituality,
 - resilience,
 - hope,
 - benefit-finding

- positive coping (divided into problem-focused coping and emotion-focused coping strategies),
- and search for meaning.

These coping strategies are briefly revisited below.

- A second circle shows the coping strategies that emerged from the clustered themes of the participants repeatedly, although they do not form part of the seven established constructs in this study. They are:
 - Distraction: going on with life (working/following a career),
 - receiving social support,
 - receiving medical support,
 - being assertive,
 - pursuing hobbies (distraction),
 - displaying inner strength,
 - cognitive restructuring and
 - performing community service.

These coping strategies are also discussed below.

- An outer circle contains the coping strategies that were mentioned once, but not emphasised, in a participant's story and which also do not form part of the seven established constructs in this study.

A proposed model with these circles are presented in Figure 12.

It is importance to emphasise that all the different parts or categories in such a model are *inter-connected*, *interrelated* and interactive. No category is completely free of the influence of any of the other categories.

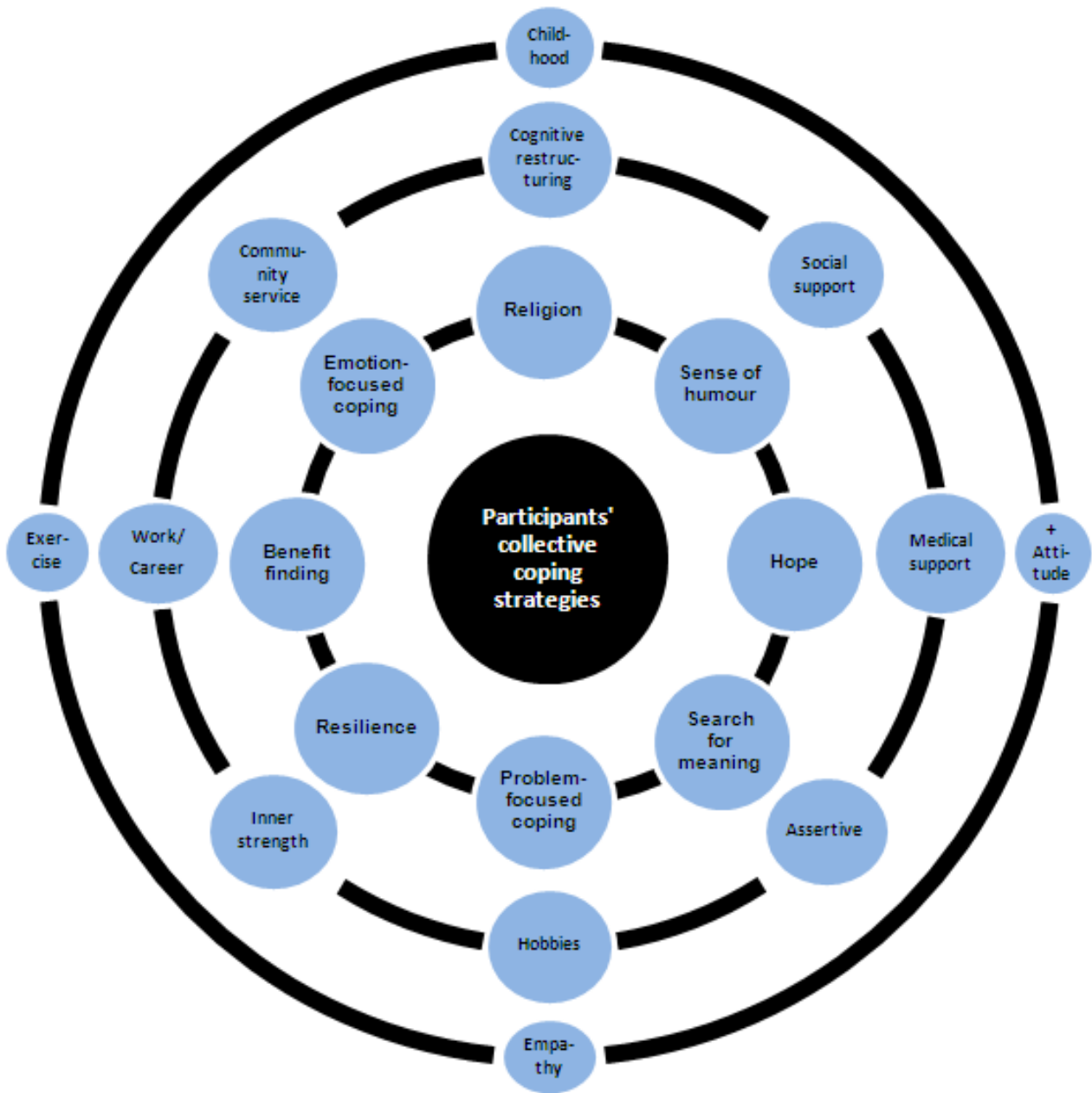


Figure 12: Towards a proposed TM coping model

6.2.2 Coping model elements

The elements of a TM coping model can now be integrated on this foundation. From Figure 12 the following twenty coping strategies emerge to populate the proposed TM coping model:



Positive coping refers to the tenacity and ability to overcome critical events that challenge a person. *Positive emotions* are connected to *positive coping* because positive emotions stem from the ability to find positive meaning (Fredrickson, 2005). Positive coping is divided into *problem-focused coping* and *emotion-focused coping*. TM patients cope better in the long run if they practice problem-focused positive coping, but emotion-focused positive coping has more immediate short term benefits.



People can sometimes relieve immediate stress by "letting off steam" or crying their hearts out. In this study Cate illustrates positive coping by refusing to show any self-pity. She rather focuses on her needlecraft and even takes her sewing machine along to all her meetings. Her husband assists her with practical problems. Because Cate cannot sit, her husband elevated all the tables in their home and they enjoy their meals standing.

Hope: Averill, Catlin and Chon (1990) described hope as an emotion governed by cognitions. According to them, environment is highlighted as having an effect on the deterioration or development of hope. They explain that hope is most appropriate when goals are (a) under control, (b) reasonably attainable, (c) acceptable at a moral and social level and (d) viewed as important by an individual.



In this study Drew advocates hope by stressing that one should hold onto one's dreams and faith. She says: *Believe in yourself ... Sometimes life turns its back on me but I firmly believe that the sun will always shine on me.*



Sense of humour: On the emotional side, humour improves therapeutic relationships, releases hostile feelings, reduces resistance to help and lessens anxiety and embarrassment incurred during times of adversity (Adamle & Turkoski, 2006). It is not possible to avoid all aversive situations in life. We live in environments that are filled with distress.

It is critical to be able to use communication such as humour to cope with stressors and at the same time remain happy and productive. Eric and his disabled colleagues use sense of humour to cope. The humour they display in calling themselves *die Lamgatbende* capture this way of coping.

Religion and spirituality: Pargament and Hahn (1986) found that participants turned to religion when they were confronted with negative events. They also found that the participants viewed religion more as a source of support for difficult times than thankfulness in happy occasions. Religious experiences cannot only be seen as important for the painful times of living. It can also not only be viewed as a way of coping. Religious involvement has a significant positive influence on psychological health.



Drew has a strong *religious connection* in her belief system which emphasises prayer. This is echoed by her gratefulness towards her husband. She expresses her joy when she speaks about %the wonderful God we all worship.+ When medical staff spoke to her about religion it was %a fantastic experience+that strengthened her in her faith.



Resilience: Tugade and Fredrickson (2004) describe psychological resilience as an ability to bounce back from challenging emotional experiences by utilising flexible adaptation methods to cope with the demands of stressful experiences. They state that research finds resilient individuals to be zestful, open to new experiences, optimistic and with high positive emotionality. As an important element of psychological resilience, positive emotionality emerges.

Highly resilient people are individuals that cultivate their positive emotionality proactively by using a sense of humour, optimistic thinking and relaxation techniques. Anne copes with TM by being resilient. She remembers growing up in a children's home. There she learned to fend for herself from an early age and to understand that life is about facing challenges head-on.

Searching for meaning: According to Baumeister and Vohs (2005), *meaning-making* refers to an active process through which people reappraise and revise a specific event or a series of events in order to find some positive meaning. This concept links with the process *from adversity to prosperity* and with benefit-finding, discussed below. The second aspect of meaning-making involves looking for acknowledgement in the effort to understand the event. This is the *sense-making function of meaning-making*.



It can be argued that all facets of human life evolved because of the fact that they serve a purpose and that it is a part of a grand evolutionary plan. Drew, indeed, finds *meaning in her life* because she works as a full-time bookkeeper. She finds meaning by keeping herself busy. Eric finds *meaning in life* and feels useful in advocating the plight of people with disabilities. He also uses his disability to the advantage of other physically handicapped people by repairing wheelchairs in lieu of the employment he used to have.

Benefit-finding: Pakenham (2007) states that *benefit-finding* could be defined as the identification of benefits during adversity. He proposes that successful adaptation in the midst of adversity is about finding benefit in suffering. Benefit-finding is the form of *cognitive adaptation* where individuals evaluate circumstances in a positive way. This brings about a sense of mastery that preserves self-esteem and assists people to process negative events mentally.



From his illness Eric *finds benefit* for himself and his marriage, because he says TM made him a better person. His wife and daughter are his care-givers and he views this in a positive light.

Social support: According to Uchino (2004) there are at least four functions of social support with any loss, namely emotional support, tangible support, informational support and companionship support. Social support is vital to effective processing and eventual acceptance. In the case of the physically disabled, social support may be the patient's utmost helper.



It is important to note that *social support* emerged as a salient coping construct. At the same time this study is aimed at supporting TM patients by supplying a proposed TM coping model.

TM support groups globally are focused on group members. TM patients are encouraged to join a TM support group and benefit from assistance from the group. Members share valuable information with one another and socialise. They benefit from general support and interaction with the entire affiliation of TM support groups.

Anne's *social support* helps her to cope with TM. Her fiancée and his family, all her close friends and colleagues shower her with incredible support and love. Eric explains that his wife and family are the best and that he will not exchange them for anything in the world.

Distraction: going on with life (working/following a career):

Participants who wrote about their jobs and careers and that their jobs helped them to cope, highlighted their daily economic activity as meaningful in their lives. Employment holds significant economic and emotional benefits for patients, provided that the lay-out and facilities in the workplace enable individuals to continue working (Johnson, Yorkston, Klasner, Kuehn, Johnson & Amtmann, 2004).



Anne copes with TM by going to work and by improving her place of work. Her active promotion of the plight and rights of people with disabilities give meaning to life in improving other peoples lives. She started a petition for her employer, the provincial

legislature, to make the building more accessible as there are three levels with neither lift facilities nor ramps for wheelchairs.



Community service: From this study, community service appeared to provide a feeling of belonging to the community. Eric, who fixes wheelchairs for other disabled people, has a sense of pride in doing so. Anne performs community service in her advocacy for the rights of disabled people. Post (2005) explains that altruistic emotions and behaviours are associated with better well-being, health and longevity. A strong correlation exists between the happiness, well-being, health and longevity of people who are behaviourally and emotionally compassionate to others. (There is however a danger of overdoing this to own detriment.)

Eric copes with his TM by participating in the spreading of knowledge about TM. He also helps paraplegics with information resources. Furthermore, he assists other handicapped people by repairing their wheelchairs.

Positive attitude: Fredrickson (2005) found that when people are under the influence of positive emotions, their awareness expands. She proposes that such people literally see more and that their peripheral vision expands. On the other hand, negative emotions narrow a person's thinking. She also found that people who increase their positive emotions develop closer connections with others.



The optimism and resilience of people with a positive attitude is strong. They are less depressed and more satisfied with life. Anne's positive attitude helps her to cope with TM. Her positive outlook and her philosophy of self-determination, coupled to her experience of childhood hardship, characterises her positive outlook on life.



Physical exercise: Hutzler and Bar-Eli (1993) found that psychological constructs expressed within an empowerment model of (a) performance accomplishments and functional efficiency, (b) perceived self-efficacy, (c) self-concept and self-esteem, (d) personality

disorders, mood states and locus of control and (e) activity level and social acceptance, correlated positively with physical exercise and activity in disabled people, when applied properly.

Bert does regular physical exercise to help him cope with TM. He used to be a good sportsman and he still exercises moderately to keep himself healthy and fit.

Medical support: Regarding professional medical support, it is highlighted by the participants' stories that sufficient support from medical staff in private practice, hospitals and rehabilitation centres are invaluable in the process of coping with TM. Professional support includes general information regarding TM, knowledgeable medical predictions regarding the prognosis, information about the various possible treatments, as well as warmth and empathy towards the TM patient.



Drew praises the support and professional assistance of physiotherapists who take her to the swimming pool. This creates pleasant times in Drew's life.

Empathy and assertiveness: Mnookin, Peppet and Tulumello, (2007) explored two dimensions: *empathy* and *assertiveness*. Empathy refers to the process by which people demonstrate an understanding of their counterpart. Assertiveness refers to the process by which a person articulates and advocates his or her interests. Although many people experience empathy to be incompatible with assertion and vice-versa, the most effective persons develop expertise along both dimensions. Disabled people who develop both the skills of being empathic and assertive can cope better.



Anne has an *empathetic understanding* of others and she copes by being empathic towards others. She sees much that she can do for others. She explains that people should commit themselves to becoming actively involved and stand together to make a concrete difference in someone else's life.



From the participants' stories in this study, it became apparent that self assertiveness was an important factor to cope with TM. An example is where Anne asserted herself at her workplace because of inadequate access to the building for disabled employees. After a certain amount of assertive effort, the workplace is now suitable for wheelchair access to the building.

Cognitive restructuring: Cognitive restructuring is a psycho-therapeutic process of learning to identify and dispute irrational thoughts, such as all-or-nothing thinking (splitting), magical thinking and emotional reasoning, which are commonly associated with many mental health disorders (Martin & Dahlen, 2005). Cognitive restructuring can help people with TM to take steps in a positive direction through positive affirmations, accurately assessing the TM situation, aligning expectations and reducing stress. Changing certain negative beliefs and energy can have a powerful effect on stress reduction, which in turn can ease emotional and physical pain.



Cate copes by means of *cognitive restructuring*. She reckons that other people are worse off than her and that TM is a small problem compared to some problems experienced by other people.



Learning to cope from previous experiences: People who learn to control their inner experiences are able to establish the quality of their lives, which is as close as any of us can come to being happy (Csikszentmihalyi, 1990). The most satisfying experiences occur following deliberate effort to accomplish something complex and worthwhile. Such experiences are not automatically pleasant at the time they take place, yet optimal experiences add up to a sense of mastery, or perhaps, better, a sense of *participation* in shaping the content of a life.

Anne utilises her challenging childhood experiences to cope with her life with TM and to add to a sense of participation in shaping the content of her life.

Inner strength: Inner strength is about having the resources and the mental skills to confront difficulties of all kinds. When a person has inner strength, he or she has a cornucopia of psychological energy and stamina build upon lived experiences of practiced humility, gratitude, love, forgiveness, control, wisdom, hope, resilience and many more positive psychological constructs (Snyder & McCullough, 2000). When facing a challenge that drains him or her of energy and inner strength, the person has enough left in him- or herself to be happy. TM patients can use their inner strength to cope with this disease.



Inner strength helps Cate to cope with her situation. She *does not display any form of self-pity* and she has no sympathy with poor people. She manages her own emotions by fighting her moments of despair and she feels that she needs to be strong to fight her own TM problems.



Pursuing hobbies (distraction): Following extensive research Reynolds (2000) lauded the therapeutic value of creative activity. An interesting hobby requires (and receives) intense concentration which then provides distraction from fret and relief from depressive thoughts. Creative activity builds self-esteem, causes positive mood-changes and yields a better sense of empowerment or control.

Because of the social contact component and other factors, involvement in creative arts combats depression. People often choose their favourite creative activity in adulthood, commonly in response to stressful life events and with some awareness of its therapeutic potential. TM patients, who pursue hobbies, such as woodwork, pottery, gardening or cooking utilise this coping strategy to serve as a distraction from the disease. Cate copes with TM by emphasising her love for needlecraft. She prioritises this hobby which gives her great joy on a daily basis.

6.3 Proposed TM coping model

Based on the coping model elements described above and following the precedents set in the literature on coping models as discussed in chapter 2.3, a proposed coping model for the well-being of patients with TM has been developed. It consists of a model description accompanied by a concomitant graphic representation similar to the one illustrating Moos and Holahan's (2007) model as shown in Figure 3. It must be pointed out that the coping model for the well-being of patients with TM as proposed in this research is intended for TM patients specifically. In this context it therefore augments Moos and Holahan's model, which addresses patients with chronic illness and disability in general.

6.3.1 Identifying coping strategy categories

In analysing the different coping strategies it was found that the strategies present themselves in various categories that will relate to the needs of TM patients at different times and under different circumstances. The following categories were identified:

- **Behavioural coping strategies** which relate to actions and reactions, mostly by patients, but also by people responding to them, e.g. in social settings. These coping strategies are employed when there is a need for firm and decisive action in addressing a TM need or a crisis. Taking problem-solving action entails learning how to take control. This means to control TM symptoms, to minimise the side effects of medication and to plan regular visits to the neurologist, physiotherapist and gym.
- **Cognitive coping strategies** which emphasise objective and rational intellectual approaches to the challenges under consideration. An appraisal of the personal significance of TM takes place and a secondary appraisal takes place when a patient evaluates the controllability of TM and compares the controllability to his or her coping resources. Cognitive strategies are used by TM patients to accept their realities. By changing their priorities and focusing on some benefit that they find from TM, they reframe their situation cognitively.

- **Emotional coping strategies** following from a person's inner and subjective feelings and reactions to TM. Emotional self-management affects the adjustment of TM patients. TM patients may benefit from an enhancement of their ability to manage their emotions.
- **Social coping strategies** which rely on the presence of and interaction with other people or groups of people in addressing problematic situations. TM patients may maintain social ties and may be positive about the social support they receive. TM support groups provide educational information as well as emotional support. This leads to minimised aloneness and better coping strategies.

Each of the above categories combines a set of strategies that are used in reaction to a specific context. The context of a TM patient is important when coping strategies are employed. No two TM patients find themselves in exactly the same context. People differ in aspects such as gender, socio-economic status, age or culture, but their contexts also differ in a plethora of more subtle ways that varies continuously. The specific contexts of TM patients highlight aspects such as uncertainty, threatening physical symptoms and disabilities. Every aspect may be treated with a different sense of significance by a specific patient.

6.3.2 Associating coping strategies with coping strategy categories

In stratifying the strategies that were discussed above, it crystallises that strategies hardly fit completely into the defined limits of a single category. Elements of the nature of a strategy invariably transgress from one category into another.

A person employing humour as a coping strategy may find that it becomes part of his or her general behaviour, while humour may actually be defined and characterised by the emotional reaction it causes in a person. It is also a very powerful strategy in social interaction. It can hardly be excluded from any of these categories. This illustrates the deep seated interactivity and relatedness between all the coping strategies. A discussion will now follow to place coping strategies in one or more of the coping strategy categories within a general TM patient context.

6.3.2.1 *Cognitive coping strategies*

Benefit-finding and *searching for meaning* forms the core of this category. TM patients may find some form of opportunity in times of adversity. Benefit-finding takes place when patients for instance consider themselves to be better people for having TM, or experience a stronger bond and understanding with their life partners because of TM.

Searching for meaning contributes to the dynamic adjustment process. Patients generate meaning from their experience of a disease and from their responses to those experiences (Larsen & Hummel, 2009). Benefit-finding and searching for meaning can be viewed as interrelated.

Cognitive restructuring is a coping strategy which involves thinking about adversity in different ways. Associated problems are viewed in a more controllable way. Patients accept the true reality of their situation but they reframe their reality in a more positive light by making use of e.g. moral building inner discourse, altering priorities and altering values (Moos & Holahan, 2007).

Drawing from *inner strength* helps TM patients to positively adjust to the stressful situations that are caused by the disease. The TM patients' abilities to reach deep inside themselves by using willpower, self control and persistence result in inner strength. Developing a realistic but optimistic attitude towards TM includes the ability to use inner strength. This is often accomplished through *learning from previous (also childhood) experiences*.

Patients with *resilience* display the ability to bounce back from experienced emotional setbacks to a previous state of functioning. Resilience is especially associated with recouping lost or alternative terrain over intermediate periods of time.

There is a strong link between inner strength, learning from previous experiences and resilience. Resilience relates to inner strength and internal locus of control in reaction to difficult situations.

Medical support, in its various forms, can help TM sufferers to receive clarity concerning the specific course of the disease, to receive the correct medical treatment and to be informed about the prognosis. As soon as most medical questions are answered, the TM patient can start preparing him or herself to cope with the disease. Medical support interacts with physical exercise in that physiotherapists encourage appropriate physical exercise for TM patients.

6.3.2.2 *Emotional coping strategies*

Hope refers to a TM patient's belief in a relatively positive outcome. Hope counteracts despair and depression. Hope is a great emotional motivator for TM patients to find the courage to carry on with their lives and to prepare for an uncertain future in the best possible manner. Hope interacts with religion and spirituality because hope is a key concept in most world religions.

TM patients who are *religious or spiritual* may find comfort from their religious and spiritual beliefs and may find meaning in their personal existence. Finding companionship and spiritual comfort in *religion and spirituality* may help them cope. Religion brings hope to believers. TM patients may use religious concepts such as hope to hold on to during dark times in life. It is possible that TM patients utilise their religion and spirituality to worry less and to let go of despair. They may also focus less on their temporary suffering on earth. Searching for meaning and religion interact with each other since a search for meaning is a pursuit of answers to life's biggest questions. It concerns beliefs and faith in God.

Applying coping skills *learned from previous experience, especially childhood experiences* can be a powerful emotion-driven strategy.

Positive emotions, i.e. happy feelings, have a very important aiding effect on individuals' ability to think and function (Isen, 2004). Examples of the effect of happy feelings are enhanced, sought-after abilities that underlie innovation, creativity and problem solving in general.

TM patients who apply a good *sense of humour* enable themselves to shift their perspective and allow themselves to see situations in a less threatening light. Humorous situations help TM sufferers to distance themselves from their suffering and to truly relax for a while.

Empathy is a powerful coping strategy for TM patients. Patients who have empathy with other people benefit from it in that they divert their focus from their own suffering to those of others for important periods.

6.3.2.3 Behavioural coping strategies

Community service is an avenue for TM patients to cope with this disease. Volunteering to partake in some form of community service efforts may increase a TM patient's ownership of personal and social responsibility. Such activities may build a sound self image and boost positive feelings while decreasing any inclination towards depression and stress. Taking responsibility in a community builds *assertiveness* which is in turn applied to own coping benefit.

Physical exercise may help TM patients to reach their rehabilitation goals, to better their overall physical functioning and to deal with possible anxiety and depression.

Distraction – going on with life, working and pursuing a career – is an underlying strategy for TM patients who *pursue hobbies* to cope effectively, since the element of distraction enables them to forget about their own suffering for a while. Pursuing hobbies creates an opportunity to meet new people; it enables a TM patient to belong to a certain group and to engage in healthy social activities.

Finding social support is a way of communicating needs that can reverberate into acts of giving and receiving. It may therefore be regarded as an inseparable counter pole of community service and in the interactive process natural friendships may be forged. TM patients are invariably urged to join a TM support group in their country. Support groups provide moral support, supply medical information, organise social activities and give advice on general problems relating to TM. By taking the necessary behavioural steps to make use of such opportunities, the coping position of the TM patient is strengthened. Doing *physical exercise* in a communal environment such as a gymnasium or sport club is a similar behavioural coping strategy with social benefits.

6.3.2.4 Social support coping strategies

This category forms a strong link in the contextual interrelatedness of all the other coping skills, in that the strategies in this category also appear in other categories. The following strategies have already been highlighted in the previous paragraphs:

- community service,
- rendering social support,
- continuing with life, work and career,
- finding the social element from medical support services,
- doing physical exercise in social settings and
- attending religious meetings.

6.3.3 Combining strategies, categories and context into a model

The model proposes that TM patients' reactions to developments in their disease (or context) can be managed by suggesting the use of specific coping strategies relevant to the context and the person. Being ready to cope when the need arises is facilitated by patients consciously preparing themselves with knowledge and experience (practice) beforehand, hence the need for a coping model.

Interrelated strategies augment each other and, as a situation develops, different strategies from different categories may be required and wilfully selected by a patient to cope. Strategies from the proposed TM coping model may serve to prevent a decline in TM patients' psychological health. The relevant coping strategies have the potential to prevent a potential vicious cycle of anxiety, depression and further decline.

Employing effective coping strategies might help TM patients to think, feel and act more positively and to engage in social interaction. The cognitive, emotional and behavioural coping categories in a systemic model not only have a significant influence on one another, but might also have an influence on a TM patient's ability to socially interact with other people. If a TM patient engages in negative thoughts, his or her whole disposition may turn negative and culminate in negative behaviour. When a TM patient's thoughts, feelings and behaviour are positive, he or she may experience improved relationships with other people. A TM patient's strategic coping with the disease influences his or her emotions, behaviour and social interaction.

The proposed TM coping model can also be viewed as a proposed psychological health cycle. The proposed interventions in this coping model have an impact on all the coping categories. Coping strategies return the patient to the context, but then a new, richer, coping context from where the psychological health cycle can again react to new contextual challenges.

6.3.4 Presenting the proposed model

A proposed model for the well-being of TM patients can now be construed on the basis of the combined strategies, categories and context. An illustration of how such a model can assist a TM patient to cope can be found from one of the participants in the study. Despite the fact that Anne was never formally coached according to a unified and formulated model, she seems to have gathered the bulk of it from her life experience and to have applied it.

Anne copes cognitively because she displays constructive, intellectual and rational abilities. She found meaning in her TM experience and she is able to be resilient. She learnt from her childhood experiences and applies these previous experiences cognitively. She copes with TM on an emotional level because she has empathy for other people, has hope for the future and these strategies assists her to act positively in order to assist other people with disabilities. Her spirituality and religious approach assists her to remain positive and her positive attitude enables her to actively become involved in her society and to engage in social activities.

Apart from having taken part in the study unselfishly together with the other participants, it seems that Anne has somehow presented a benchmark for refining the model, as has indeed been done through repeated discussions with various knowledgeable parties.

The resultant proposed model is now presented in

Figure 13. In addition to the elements of the models as discussed, the model is also supplied with process information indicating close clusters of strategies in curly brackets and showing origins and feedback paths in single and double headed arrows.

In presenting a coping model for the well-being of patients with TM, based upon the preceding analysis, the third and last objective of the research, as presented in chapter 1.5, has been satisfied.

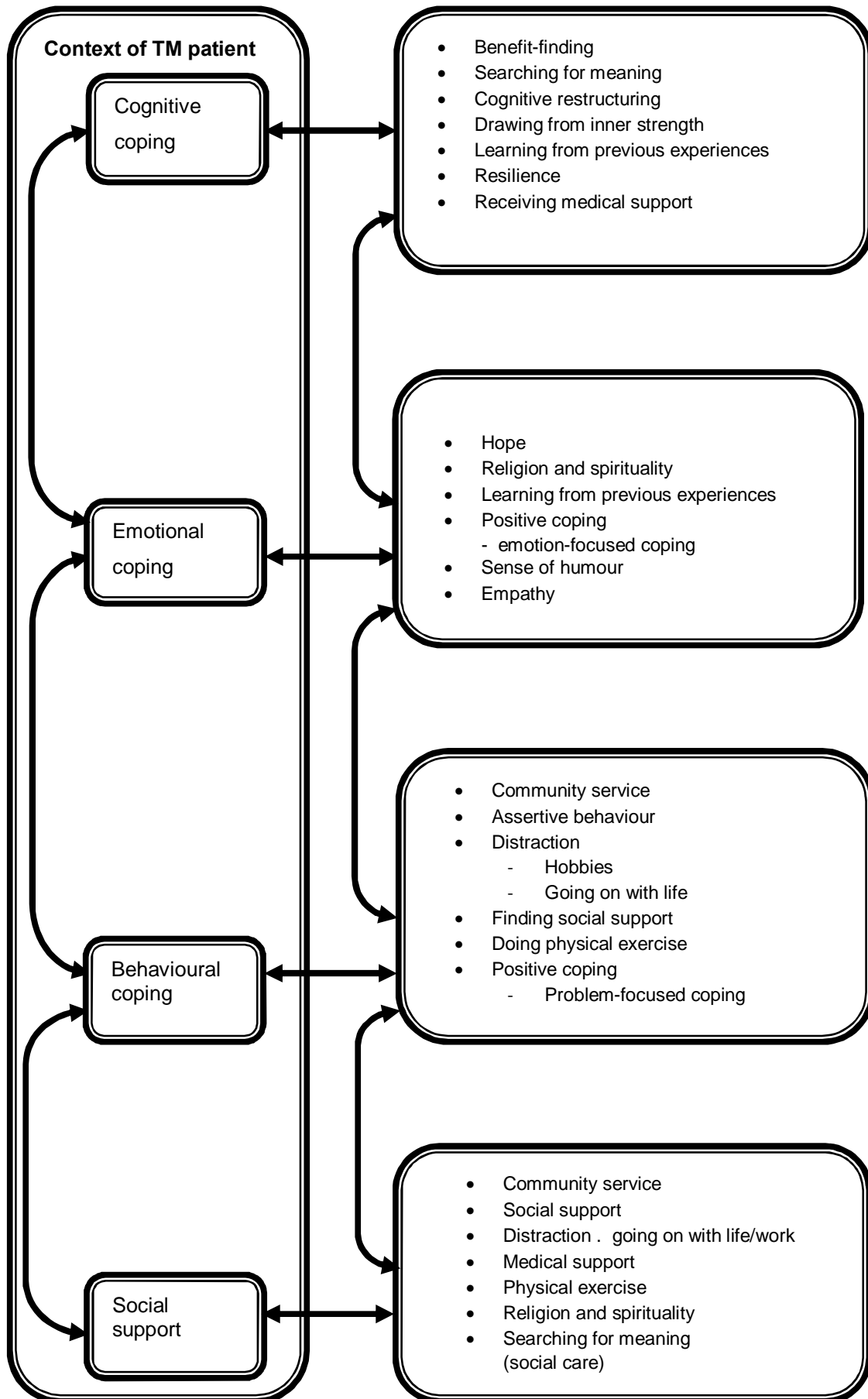


Figure 13 Proposed coping model for the well-being of TM patients

6.4 Empowering TM patients to benefit from the proposed model

It is believed that the proposed coping model for the well-being of patients with transverse myelitis may open an academic discourse in this regard, as no other existing models for this purpose and this specific grouping could be found. From that point of view the aims of this research have therefore been achieved.

It is, however, highly unlikely that many patients with TM or their caregivers would even consider consulting an academic thesis for guidance in coping during a sudden crisis. To make the proposed model valuable to people in such circumstances, it would be necessary to present the information to them in a more palatable format.

This thesis is not the correct forum for developing a presentation set that may consist of articles in Transverse Myelitis Association (TMA) newsletters, audio-visual material, pamphlets or personal dissemination. Suffice it to state that such material may be based on the research results of the study or others to follow and may include expanded descriptions and guidelines along the lines of the description of coping model elements in paragraph 6.2.2.

A *model face* for the use of TM patients has been developed as an *aide memoire* for the quick recall of coping skills when needed. This model face is presented in Figure 14. It is believed that, if a TM patient is *au fait* with the supporting material, the model face will "come alive", so that it forms a quick reminder of all it represents. It can remind TM patients of the coping strategies in their armoury when they are sorely needed.

In the model face the position and size of each icon represents the frequency and intensity of use of coping strategies as gathered from the literature and contributed by the stories of the five participants. The fact that this model face has been developed especially (but not exclusively) for and with the help of TM patients is indicated by the dorsal neuron background of the representation.

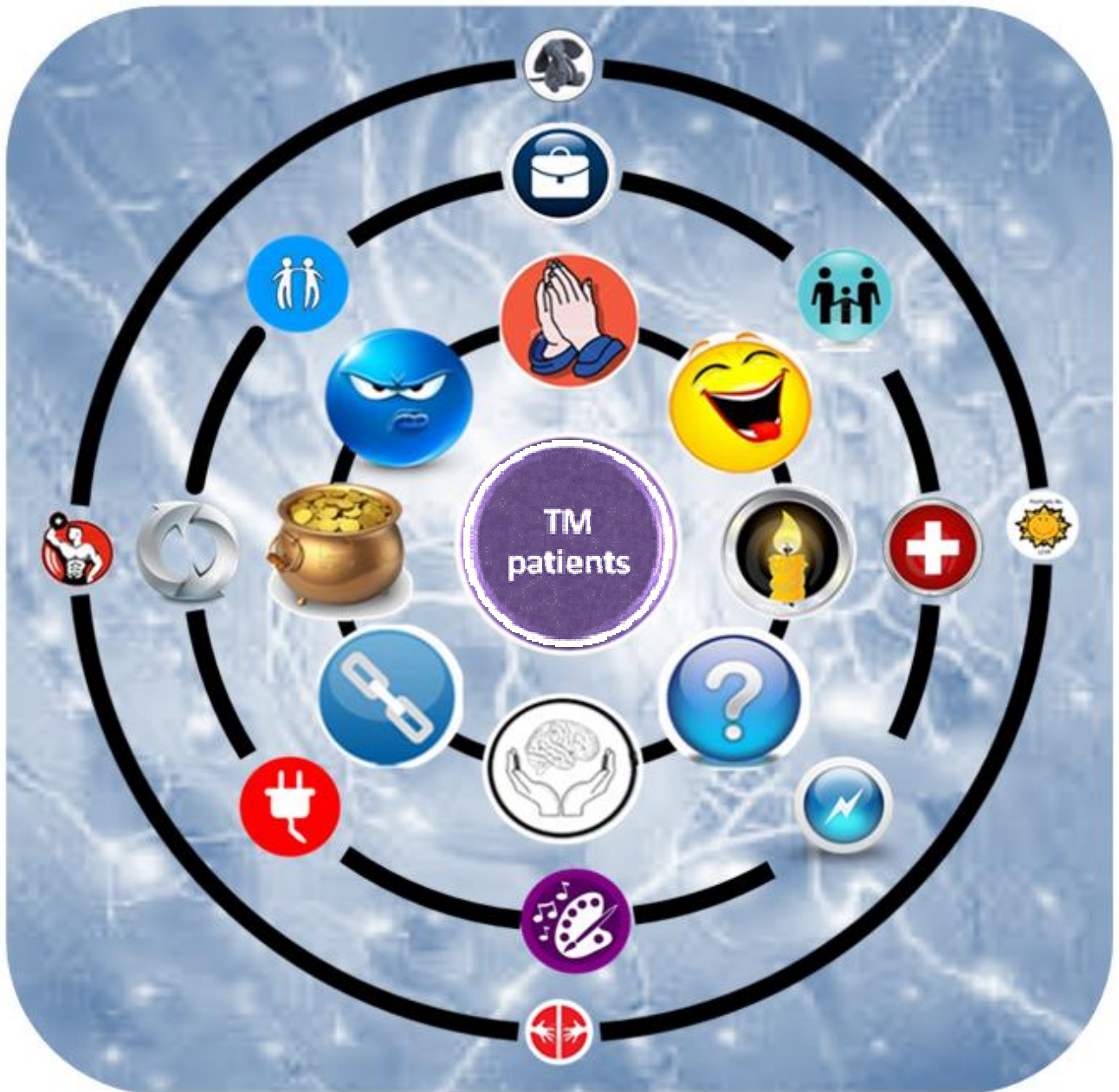


Figure 14 Model face for the use of TM patients

6.5 Chapter conclusion

In this chapter, based on the findings of the research, the literature study (in chapter 3) and existing coping models, a coping model for TM patients is proposed.

The model illustrates that the separate coping strategies of TM patients are interconnected and inter-related and that these constructs cannot be applied in isolation. The inter-relatedness of the constructs in the proposed TM coping model reveals that an attempt to cope with TM necessitates an intense, complex process that requires emotional, cognitive, behavioural and social strategies.

To enable TM patients to utilise the results of this study, material with a less academic and more practical slant will have to be prepared and provided on the strength of this study. As precursor to compiling such material, a model face or graphic aid is offered to help patients internalise the coping strategies.

In the next chapter (chapter 7) the research process is critically discussed, conclusions and recommendations are made and ideas for the dissemination of the research findings are suggested. Recommendations regarding the application of the proposed TM Coping Model are offered.

Chapter 7

Critical comments and recommendations

7.1 Introduction

In this chapter known shortcomings in the research processes that were followed will be identified and limitations concerning the applicability of results will be indicated. Avenues and options for further research which can build upon the findings are suggested and recommendations are made for utilising results to the benefit of TM patients.

7.2 Critical evaluation of the study

In this study five patients who experienced TM for more than five years were approached to write their stories about their experiences with TM and to send it to the researcher by e-mail. The researcher analysed their stories in terms of the positive strategies they use to cope with the illness. All of them wrote of the difficulty of the illness but also about ways that helped them to find it bearable to live with the disease. They wrote how they found meaning in illness and how their lives are carrying on with improved relationships. There was a reverberating richness in the data they contributed. They mentioned how they continue to contribute to society. They used various skills and strategies that they employ to carry on with their daily lives.

This research resulted in a categorisation of coping skills that could help other TM patients to deal with the illness. As was envisaged from the onset, a proposed coping model for the well-being of patients with TM was duly developed, refined and presented. This is in line with the title of the thesis that was approved by the Ethics committee of the Faculty of Humanities of the University of Pretoria before the study commenced.

Caveats for the application of the results are already embedded in the title of the thesis. The work was limited to the field of coping with TM. Because the research was conducted primarily to meet a need, namely to render the South African TM Support Group more efficient in assisting its members to cope, it was also done in the specific locale of South Africa. Although an in depth literature study was done using global resources, only contributions relevant to the stated objectives were presented in the thesis and contributions from participants were all gathered in South Africa. The proposed model is not intended to be a cure all for all patients. It is not even a psychological cure-all for TM patients. It is only a proposed model to assist TM patients and their care-givers to open their minds for positive ways of coping with their situations.

The model was developed according to the data of a relatively small group of TM patients. It integrated existing constructs and models from the broader field which serves to mitigate some of the limitations of the study. Some of the coping strategies of the five participants might not apply to, or be useful to all TM sufferers in South Africa or in the rest of the world.

The nature of research in a humanitarian realm differs from that in an industrial realm. Because this research was privately funded it was done by a small team that took longer, but could afford to be more meticulous as their overhead costs were minimal . as was the budget. The background study and model development, after the analysis of results, was the task of the main researcher alone.

More costly face to face interviews as data collection tools could have conveyed more information about the participants. In the e-mail correspondence facial expressions, general body language and finer nuances were lost to the researcher. Another critique is that it might have proven to be more effective for every participant to furnish a series of separate, follow up stories over time, like the participant with the pseudonym *Bert* did. Bert was in a significantly different frame of mind in the follow up story, compared to the initial story.

This research was done using the IPA approach. It has various advantages but also include some limitations. The research focuses on in-depth analysis of a purposive sample. A larger sample of respondents could have produced different perspectives on ways of coping with chronic disease. Similarly, if another group of participants would have been used, it could have resulted in different results. Participants from other socio-economic circumstances could have been considered for the study.

Because the researcher only made use of information obtained via e-mail, only participants with access to internet facilities contributed. It could therefore be hypothesised that the participants used in this study fall in a socio-economic category that enables them to obtain medical assistance as well. There may be unidentified TM sufferers in South Africa that can not even afford to become known to the support group. If the researcher corresponded with them, the results could possibly have differed completely. Less fortunate people may have difficulty in getting a proper diagnosis and may live in near isolation.

The participants used in this study are all members of the TM support group and have therefore received support. If it was possible for the researcher financially, geographically, linguistically and practically to approach TM patients that are not part of the South African TM support group, the results could have been different. It can be acknowledged that the researcher was continuously at peril of trying to achieve too much with too little, but that is a normal human predicament. It is therefore trusted that this thesis presents groundwork that can form a basis for further research.

7.3 Recommendations for further research

With regard to the psychological care of TM patients, a research gap was filled with this study because very little research results and psychological information are available as TM is a neglected disease in many ways. The coping strategies used by experienced TM patients were explored in this research. The findings can be used by other TM patients who are in need of coping assistance in their daily lives.

As a point of departure towards establishing the required interventions, it is observed that the approach of positive psychology with its emphasis on fortigenic qualities (Snyder & Lopez, 2005) was an adequate way to investigate coping lifestyles.

Although this study made no distinction with respect to gender, the input of two males and three females was analysed equally. A new contribution can be made by exploring the TM experiences of females versus males. Hereby, TM experiences have the potential to bring about a comparative study based on gender.

It is recommended that research can be conducted about the family (system) experiences of a family member with TM. Such a study could include the experiences of the direct family such as the TM patient's parents and siblings but could also include the experiences of extended family members such as aunts and uncles as well as grandparents. Care-givers could also include friends and therefore friends of a TM patient could be consulted to obtain their experiences of how to cope with the illness of their friend.

Coping with TM could be measured quantitatively via questionnaires, which could convey the results statistically. Different weights could be assigned to specific constructs in such questionnaires. The statistical results could then be construct-specific.

It could be hypothesised that babies and young children have better coping strategies to deal with TM because their sense of loss related to physical capability is probably not as pressing as that of an adult person. It could prove to be significant to research this aspect of TM in a follow up study.

7.4 Recommendations for applying the research results

Because this research achieved what it set out to do, the results are already being applied in the lives of the participants. The TM patients that participated in the research have learned to draw on their coping skills in strenuous times and have

started communications with their Support Group leader about psychological challenges, as both parties are more ready and better equipped to approach the subject as a result of the research.

It is now intended to transport the essence of the proposed model, as captured in the thesis, onto appropriately designed pamphlets as patient guidelines that can be furnished to patients by the SA TM Support Group as needs arise or as they are identified or even only suspected. A simple fridge magnet with supporting pamphlets representing the combined TM coping elements may just prove invaluable to a single patient somewhere.

The SA TM Support Group can now embark on an active culture of coping. This can be done through communication among each other, through sharing coping stories or through workshops to make coping strategies come alive in a TM patient's mindset.

As mentioned in the acknowledgements (page iii), the CEO of the international Transverse Myelitis Association (TMA), Dr Sandy Siegel, took a personal interest in this study and supported it in various ways. It is therefore likely that the results and resulting pamphlets may, albeit in revised ways, be utilised abroad. The proposed TM coping model will be communicated through the international TMA newsletters.

The website of the SA TM Support Group can form a portal to a three-dimensional representation of an interactive revolving planetary representation of the proposed model, especially for the emerging iPad community. The model can then be manipulated digitally (in both senses of the word) to bring strategies to the fore that can be pressed for more information. Clicking can bring forth appropriate text, videos, scripture, music or web pages. Such a presentation can be refined extensively if the impetus and need exist. Pressing simultaneously on any two strategies could open up linkages. Pressing *Hope* and *Religion* together can bring forth text, videos, scripture, music or web pages regarding *Hope in Christianity*, *Hope in Islam*, *Hope in Judaism*, *Hope in Buddhism*, *Hope in Hinduism* for instance.

Despite the academic disclaimers of section 7.2, the research results may well find application beyond the originally intended scope. TM sufferers in other countries may come to benefit. This study could be of value to physicians (including neurologists), psychologists, care-givers and family when dealing with TM patients. Such people can even benefit by being made aware of the various coping strategies and resources of TM patients. Hopefully, the findings and proposed material can serve as guidelines for TM patients that were recently diagnosed, as well as supply them with valuable information.

It would have been strange if someone undertook a mission like this research, pursued it enthusiastically and attained results, but did not benefit at all. Of course the researcher grew in her understanding of TM, her understanding of positive psychology, her understanding and adeptness at coping and her understanding of herself.



"The world is a den of thieves and night is falling. Evil breaks its chains and runs through the world like a mad dog ... No one escapes, not even our children. So it shall be. Therefore, let us be happy while we are happy. Let us be kind, generous, affectionate and good. It is necessary, and not at all shameful, to take pleasure in the little world. Good food, gentle smiles, fruit trees in bloom, waltzes."

. Ingmar Bergman.

References

- Ackroyd, K., Fortune, D. G., Price, S., Howell, S., Sharrack, B., & Isaac, C. L. (2011). Adversarial growth in patients with multiple sclerosis and their partners: Relationships with illness perceptions, disability and distress. *Journal of Clinical Psychological Medicine*, *18*(4), 372-379.
- Adamle, K., & Turkoski, B. (2006). Responding to patient-initiated humor: Guidelines for practice. *Home Healthcare Nurse*, *24*(10), 639-644.
- Affleck, G., & Tennen, H. (1996). Construing benefits from adversity: Adaptational significance and dispositional underpinnings. *Journal of Personality*, *64*, 899-922.
- Alessandri, M., Heiden, L., & Dunbar-Welter, M. (1995). History and Overview. In L. Heiden & M. Hersen (Eds.), *Introduction to clinical psychology*. New York: Plenum Press.
- American Psychiatric Association (APA) (1994). *Diagnostic and statistical manual of mental disorders, Fourth Edition*. Washington, DC: American Psychiatric Association.
- Anderson, N. B., & Anderson, P. E. (2004). *Emotional longevity*. Washington: Penguin Group.
- Antonovsky, A. (1979). *Health, stress and coping*. San Francisco: Jossey-Bass.
- Antonovsky, A. (1987). *Unraveling the mystery of health – how people manage stress and stay well*, San Francisco: Jossey-Bass Publishers.
- Antonovsky, A., & Sagy, S. (1990). Confronting developmental tasks in the retirement transition. *Gerontology*, *30*, 362-368.
- Aronson, J. (1994). *A pragmatic view of thematic analysis*. (n. D.) Retrieved on 23 May 2007 from <http://www.nova.edu/ssss/QR/BackIssues/QR2-1/aronson.html>
- Averill, J. R., Catlin, J., & Chon, K. K. (1990). *Rules of hope*. New York: Springer-Verlag.
- Avia, M. D. (1997). Personality and positive emotions. *European Journal of Personality*, *11*, 33-56.
- Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychologist*, *37*, 122-147.

- Barlow, D. H., & Durand, V. M. (1999). *Abnormal psychology. An integrative approach*. (2nd edition, 53). California : Brooks/Cole.
- Baskin, F., Rosenberg, R. G., & Greenberg (1991). *Neuroscience Research*. 29, 127-132.
- Basson, P., Fouche, B., Saaiman, C. I., & van Eeden, C. (2001). *Psychology of well-being: PSY 5004*. Silverton, Pretoria.
- Battista, J., & Almond, R. (1973). The development of meaning in life. *Psychiatry*, 36, 409-427.
- Baumeister (1991). *Meanings of life*. New York: Guilford.
- Baumeister, R., & Vohs, K. (2005). Meaningfulness in life. In C. R. Snyder & S. Lopez, *Handbook of positive psychology* (pp. 608-618). Oxford UK: Oxford University Press.
- Berman, M., Feldman, S., & Alter, M. (1981). Acute transverse myelitis: Incidence and etiological considerations. *Neurology*, 31, 966.
- Beuhler, J. A. (1975). What contributes to hope in the cancer patient? *American Journal of Nursing*, 75, 1353-1356.
- Biggerstaff, D., & Thompson, A. R. (2008). Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research. *Qualitative Research in Psychology*, 5(3), 214-224.
- Bjorck, J. P., & Cohen, L. H. (1993). Coping with threats, losses and challenges. *Journal of Social and Clinical Psychology*, 12, 105-120.
- Bower, J. E., Low, C. A., Moskowitz, J. T., Sepah, S., & Epel, E. (2008). Benefit finding and physical health: Positive psychological changes and enhanced allostasis. *Social and Personality Psychology Compass*, 2(1), 223-244.
- Breed, M. (1997). *Bepalende persoonlikheidskenmerke in die salutogeniese paradigma*. (Unpublished doctoral thesis.) University of South Africa, Pretoria.
- Breznitz, S. (1986). The effect of hope on coping with stress. In M. H. Apley & P. Trumbull (Eds.), *Dynamics of stress: physiological, psychological and social perspectives* (pp. 295-307). New York: Plenum Press.
- Bryman, A. (1988). *Quality and quantity in social research*. London: Unwin Hyman.

- Bury, M. (1982). Chronic illness as biographical disruption. *Journal of Sociology of Health and Illness*, 4, 167-182.
- Carr, A. (2004). *Positive psychology: The science of happiness and human strengths*. London: Bruner-Routledge.
- Chalk, H. M. (2007a). *Coping with multiple sclerosis: Coping strategies, personality and cognitive appraisals as predictors of adjustment among multiple sclerosis patients*. (Unpublished doctoral thesis.) Ohio State University, Ohio, USA.
- Chalk, H. M. (2007b). Mind over matter: Cognitive . behavioral determinants of emotional distress in multiple sclerosis patients. *Psychology, Health & Medicine*, 12(5), 556-566.
- Charmaz, K. (2000). Grounded theory: Objectivist and constructivist methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed.) (pp. 509-535). Thousand Oaks, CA: Sage.
- Christie, W., & Moore, C. (2005). The impact of humor on patients with cancer. *Clinical Journal of Oncology Nursing*, 9(2), 211-218.
- Cloud, J. (2012). Beyond Drugs: Some hurts are forever. But now science is pushing back. Time specials. Retrieved on 12 Sept 2012 from http://www.time.com/time/specials/packages/article/0,28804,2053382_2055269_2055260,00.html
- Compas, B., & Gotlib, I. (2002). *Introduction to clinical psychology*. New York, NY : McGraw-Hill Higher Education.
- Cousins, N. (1976). Anatomy of an illness (as perceived by the patient). *New England Journal of Medicine*, 295, 1458-1463.
- Covington, M. V. (2000). Goal theory, motivation and school achievement: An integrative review. *Annual Review of Psychology*, 51, 171-200.
- Crawage, M. (2005). *How resilient adolescent learners in a township school cope with school violence: A case study*. (Unpublished doctoral thesis.) University of Johannesburg, Johannesburg.
- Crist, J. D., & Tanner, C. A. (2003). Interpretation or analysis methods in hermeneutic interpretive phenomenology. *Nursing Research*, 52, 202-205.

- Csikszentmihalyi, M. (1990). *Flow: The psychology of optimal experience*. New York: Harper and Row.
- Csikszentmihalyi, M. (2000). *Beyond boredom and anxiety*. San Francisco: Jossey-Bass.
- Csikszentmihalyi, M. (2009). The promise of positive psychology. *Psihologijiske Teme*, 18(2), 203-211.
- Dahlberg, K., Drew, N., & Nystrom, M. (2001). *Reflective lifeworld research*. Lund, Sweden: Studentlitteratur.
- Danoff-Burg, S., & Revenson, T. A. (2005). Benefit finding among patients with rheumatoid arthritis. *Journal of Behavioral Medicine*, 28, 91-103.
- David, S. F., & Palladino, J. J. (1997). *Psychology* (2nd Ed.). Prentice Hall: New Jersey.
- Davis, C., Nolen-Hoeksema, S., & Larson, J. (1998). Making sense of loss and benefiting from the experience: Two construals of meaning. *Journal of Personality and Social Psychology*, 75, 561-574.
- Del Fabbro, G. A. (2006). *A family systems analysis of serial murder*. (Unpublished doctoral thesis.) University of Pretoria, Pretoria.
- Diener, E. (1984). Subjective well-being. *Psychological Bulletin*, 95 (3), 542-575.
- Diener, E., Eunkook, M. S., Robert, E. L., & Smith, H. L. (1999). Subjective well-being: Three decades of progress. *Psychological Bulletin*, 125(2), 276-302.
- Dodick D. W., Brown R. D. Jr., Britton J. W., & Huston J. (1999). 3rd. Nonaneurysmal thunderclap headache with diffuse, multifocal, segmental and reversible vasospasm. *Cephalalgia* 1999; 19: 118. 23.
- Dubree, M., & Vogepohl, R. (1980). When hope dies . so might the patient. *American Journal of Nursing*, 80, 1046-2049.
- Duckworth, A. L., Steen, T. A., & Seligman. M. E. P. (2005). Positive psychology in clinical practice. *Annual Review of Clinical Psychology*. 1, 629-651.
- Dufault, K. J., & Martocchio, B. (1985). Hope: Its spheres and dimensions. *Nursing Clinics of North America*, 20, 379-391.

- Dunne K, Hopkins I. J., & Shield L. K. (1986). Acute transverse myelopathy in childhood. *Developmental Medicine and Child Neurology*, 28, 198-204.
- Dweck, C. S. (1999). *Self-theories: Their role in motivation, personality and development*. Philadelphia: Psychology Press.
- Eitel, P., Hatchett, L., Friend, R., Griffin, K., & Wadhwa, N. (1995). Burden of self-care in seriously ill patients: Impact on adjustment. *Health Psychology*, 14, 457-463.
- Engel, G. L. (1980). The clinical application of the biopsychosocial model. *American Journal for Psychiatry*, 137, 535-544.
- Erdman, L. (1994). Laughter Therapy for Patients with Cancer. *Journal of Psychosocial Oncology*, 11(4), 55-67.
- Erickson, S. J., & Feldstein, S. W. (2007). Adolescent humor and its relationship to coping, defence strategies, psychological distress and well-being. *Child Psychiatry & Human Development*, 37(3), 255-271.
- Erickson-Klein, R. (1990). Pain Control Interventions of Milton H. Erickson. In J. K. Zeig, & S. Gilligan (Eds.), *Brief Therapy* (pp. 273-287). New York: Brunner/Mazel.
- Erikson, E. H. (1964). *Insight and responsibility*. New York: W. W. Norton.
- Esterling, B. A., L'Abate, L., Murray, E. J., & Pennebaker J. W. (1999). Empirical foundations for writing in prevention and psychotherapy: mental and physical health outcomes. *Clinical Psychology Review*. 19(1):79-96.
- Fava, G. A. (1999). Well-being therapy. *Psychotherapy Psychosomatic*, 68, 171-178.
- Finlay, L. (2003). Through the looking glass: Inter-subjectivity and hermeneutic reflection. In L. Finlay and B. Gough (Eds.), *Reflexivity: a Practical Guide for Researchers in Health and Social Sciences*. Oxford: Blackwell Publishing.
- Finlay, L. (2005). Reflexive embodied empathy: a phenomenology of participant-researcher intersubjectivity. *Methods Issue: The Humanistic Psychologist*, 33(4), 271-92.
- Finlay, L. (2006). Rigour, ethical integrity, or artistry? Reflexively reviewing criteria for evaluating qualitative research. *British Journal of Occupational Therapy*, 69(7), 319-26.

- Folkman, S. (2011). *The Oxford handbook of stress, health and coping*. London: Oxford University Press.
- Folkman, S., Chesney, M. A., Collette, L., Boccillari, A., & Cooke, M. (1996). Postbereavement depressive mood and its pre- bereavement predictors in HIV+ and HIV- gay men. *Journal of Personality and Social Psychology*, 70, 336-348.
- Folkman, S., & Moskowitz, J. T. (2000). Positive affect and the other side of coping. *American Psychologist*, 55(6), 647-654.
- Frankl, V. E. (1963). *Man's search for meaning: an introduction to logotherapy: 1963-2000*. Boston: Beacon Press.
- Frankl, V. E. (1964). *Man's search for meaning*. London: Hodder & Stoughton.
- Frankl, V. E. (1985). *Man's search for meaning: Revised and updated*. New York: Washington Square.
- Frankl, V. E. (1997). *Man's Search for ultimate meaning*. Perseus Book Publishing: New York.
- Frankl, V. E. (2000). *Viktor Frankl Recollections. An Autobiography*, Basic Books, Cambridge: MA.
- Fredrickson, B. L. (1998). What good are positive emotions? *Review of General Psychology: Special Issue: New Directions in Research on Emotion*, 2, 300-319.
- Fredrickson, B. L. (2001). The role of positive emotions in positive psychology: The broaden-and-build theory of positive emotions. *American Psychologist: Special Issue*, 56, 218-226.
- Fredrickson, B. L. (2003). The value of positive emotions. *American Scientist*, 91, 330-335.
- Fredrickson, B. L. (2005). Positive emotions. In C. R. Snyder & S. J. Lopez (Eds.), *Handbook of Positive Psychology* (pp. 120-134). New York: Oxford University Press.
- Fredrickson, B. L., Tugade, M. M., Waugh, C. E., & Larkin, G. R. (2003). What good are positive emotions in crises? A prospective study of resilience and emotions following the terrorist attacks on the United State on September 11th, 2001. *Journal of Personality and Social Psychology*, 84(2), 365-376.
- Freud, S. (1920). One of the difficulties of psycho-analysis. *International Journal of Psycho-Analysis*, 1, 17-23.

- Frischenschlager, O., & Pucher, I. (2002). Psychological management of pain. *Disability and Rehabilitation*, 24(8), 416-422.
- Fromm, F. (1973). *Foundations of behavioral research*. (2nd edition). New York: Holt-Rinehart and Winston.
- Gable, S. L., & Haidt, J. (2005). What (and why) is positive psychology? *Review of General Psychology*, 9, 103-110.
- Garnezy, N. (1973). Competence and adaptation in adult schizophrenic patients and children at risk. In S. R. Dean (Ed.), *Schizophrenia: The first ten Dean Award Lectures* (p. 163-204). NY: MSS Information Corp.
- Garnezy, N., & Streitman, S. (1974). Children at risk: The search for the antecedents of schizophrenia. Part 1. Conceptual models and research methods. *Schizophrenia Bulletin*, 8(8), 14-90.
- Godfrey, J. J. (1987). *A philosophy of human hope*. Dordrecht: Martinus Nijhoff.
- Goldschneider, A. (1920). *Das schmerz problem*. Berlin: Springer.
- Gottschalk, L. A. (1974). A hope scale applicable to verbal samples. *Archives of General Psychiatry*, 30, 779-785.
- Gottschalk, L. A. (1985). Hope and other determinants to illness. *American Journal of Psychotherapy*, 39, 515-524.
- Greenberg, S. A. (2007). A gene expression approach to study perturbed pathways in myositis. *Current Opinion in Rheumatology*, 19(6), 536-41.
- Greene, S., O'Mahoney, P., & Rungasamy, P. (1982). Levels of measures hopelessness in physically ill patients. *Journal Psychosomatic Research*, 26, 591-593.
- Grounds, M. (2008). *The relationship between meaning in life and optimism*. (Unpublished master's dissertation.) University of Johannesburg, Johannesburg.
- Groves, M. S., & Muskin, P. R. (2005). Psychological responses to illness. In J. E. Levenson (Ed.), *American psychiatric textbook of psychosomatic medicine* (p. 67-88). Washington, DC: American Psychiatric Publishing.

- Guthrie, S. (1993). *Faces in the clouds: a new theory of religion*. New York: Oxford University Press.
- Hagglund, K. J., Haley, W. E., Reveille, J. D., & Alarcon, G. S. (1989). Predicting individual differences in pain and functional impairment among patients with rheumatoid arthritis. *Arthritis Rheumatoid*, 32, 851-857.
- Heather, N. (1976). The specificity of schizophrenic thought disorder: A replication and extension of previous findings. *British Journal of Social and Clinical Psychology*, 15(2), 131-137.
- Helgeson, V. S., Reynolds, K. A., & Tomich, P. L. (2006). A meta-analytic review of benefit finding and growth. *Journal of Consulting and Clinical Psychology*, 74, 797-816.
- Henwood, K. (1996). Qualitative enquiry: Perspectives, methods and psychology. In J. T. E. Richardson (Ed.), *Handbook of qualitative research methods for psychology and the social sciences* (p. 105-124). Leicester: BPS Books.
- Heppner, P. P., & Peterson, C. H. (1982). The development and implications of a personal problem-solving inventory. *Journal of Counseling Psychology*, 29, 66-75.
- Herth, K. (1989). The relationship between level of hope and level of coping response and other variables in patients with cancer. *Oncology Nursing Forum*, 16(1), 67-72.
- Herth, K. (1990). Relationship of hope, coping styles, concurrent losses and setting to grief resolution in the elderly widow(er). *Research in Nursing and Health*, 13, 109-117.
- Hickey, S. S. (1986). Enabling hope. *Cancer Nursing*, 9, 133-137.
- Hilbert R. A. (1984). The acultural dimensions of chronic pain: Flawed reality construction and the problem of meaning. *Social Problems*, 3(4), 364-378.
- Hinds, P. (1984). Inducing a definition of hope through the use of grounded theory methodology. *Journal of Advanced Nursing*, 9, 357-362.
- Hinds, P., & Martin, J. (1988). Hopefulness and the self-sustaining process in adolescents with cancer. *Nursing Research*, 37, 336-340.
- Hoepfl, M. (1994). *Closure of technology teacher education programs: factors influencing discontinuance decisions*. (Unpublished doctoral dissertation). Morgantown, WV, USA.

- Hoepfl, M. C. (1997). Choosing qualitative research: A primer for technology education researchers. *Journal of Technology Education*, 9(1), 47-63.
- Holland, B. C., & Ward, R. S. (1966). Homeostasis and psychosomatic medicine. In S. Arieti (Ed.), *American Handbook of Psychiatry*. New York: Basic Books.
- Human, M. (2012). *A mindfulness, acceptance and commitment (MAC) approach for performance development of cricket coaches in South Africa*. (Unpublished doctoral Thesis in preparation.) University of Pretoria, Pretoria.
- Hutzler, Y., & Bar-Eli, M. (1993). Psychological benefits of sports for disabled people: a review. *Scandinavian Journal of Medicine & Science in Sport*, 3 (4), 217-228.
- Hydén, L. C. (1997). Illness and narrative. *Sociology of Health & Illness*, 19(1), 48-69.
- Irani, D. N., & Kerr, D. A. (2000). 14-3-3 protein in the cerebrospinal fluid of patients with acute transverse myelitis. *Lancet*, 355-901.
- Irving, L. M., Snyder, C. R., & Crowson, J. J., Jr. (1998). Hope and the negotiation of cancer facts by college women. *Journal of Personality*, 66, 195-214.
- Isen, A. M. (2002). The influence of positive affect on the components of expectancy motivation. *Journal of Applied Psychology*, 87, 1055-1067.
- Isen, A. M. (2004). Positive affect as a source of human strength. In L. G. Aspinwall & U. M. Staudinger (Eds.), *A psychology of human strengths: Fundamental questions and future directions for a positive psychology* (pp. 179-195). Washington: American Psychological Association.
- Jalowiec, A., & Powers, M. J. (1981). Stress and coping of hypertensive and emergency room patients. *Nursing Research*, 3, 10-15.
- Jeffrey, D. R., Mandler, R. N., & Davis, L. E. (1993). Transverse myelitis: Retrospective analysis of 33 cases, with differentiation of cases associated with multiple sclerosis and parainfectious events. *Archives of Neurology*, 50, 532.
- Johnson, K. L., Yorkston, K. M., Klasner, E. R., Kuehn, C. M., Johnson, E., & Amtmann, D. (2004). The cost and benefits of employment: a qualitative study of experiences of persons with multiple sclerosis. *Archives of Physical Medicine and Rehabilitation*, 85, 201-209.

- Kagan, S. L., Moore, E., & Bredekamp, S. (Eds.). (1995). *Reconsidering children's early development and learning: Toward common views and vocabulary*. Goal 1 Technical Planning Group Report 95. 03. Washington, DC: National Education Goals Panel.
- Kaplin, A. I., Deepa M., Deshpande, D. M., Scott, E., Krishnan, C., Carmen, J. S., & Kerr, D. A. (2005). IL-6 induces regionally selective spinal cord injury in patients with the neuroinflammatory disorder transverse myelitis. *Journal of Clinical Investigation*, *115*(10), 2731-2741.
- Kaplin, A. I., Krishnan, C., Deshpande, D. M., Pardo, C. A., & Kerr, D. A. (2005). Diagnosis and management of acute myelopathies. *The Neurologist*, *11*, 2-18.
- Kaplin, A. I. (2006). Demoralization and depression in multiple sclerosis and transverse myelitis. Retrieved from <http://myelitis.org/newsletters/v8n1/newsletter8-1-02.htm#.US4S4VQaLcs>
- Keyes, C. L. M., Shmotkin, D., & Ryff, C. D. (2002). Optimizing well-being: The empirical encounter of two traditions. *Journal of Personality and Social Psychology*, *82*, 1007. 1022.
- Klaassen, D. W., Graham, M. D., & Young, R. A. (2009). Spiritual / religious coping as intentional activity: An action theoretical perspective. *Archive for the Psychology of Religion*, *31*, 3-33.
- Kleinman A. (1988). *The illness narratives: suffering, healing and the human condition*. Basic Books, University of Michigan.
- Koenig, H. G., Larson, D. B., & McCullough, M. (2001). *Handbook of religion and health*. New York: Oxford University Press.
- Korner, I. N. (1970). Hope as a method of coping. *Journal Consulting and Clinical psychology*, *34*, 134-139.
- Krägeloh, C. U., Pei Minn Chai, P., Shepherd, D., & Billington, R. (2010). How religious coping is used relative to other coping strategies depends on the individual's level of religiosity and spirituality. *Journal of Religion and Health*, *51*(4), 1137-51.
- Kralik D., van Loon A., & Visentin K. (2006). Resilience in the chronic illness experience. *Educational Action Research* *14*(2), 187. 201.
- Krishnan, C., Kaplin, A. I., Deshpande, D. M., Pardo, C. A., & Kerr, D. A. (2004). Transverse myelitis: Pathogenesis, diagnosis and treatment. *Frontiers in Bioscience*, *9*, 1483-1499.

- Lamb, R. (1988). A will to live. *The Canadian Nurse*, 84(3), 30-33.
- Larsen, P., & Hummel, F. (2009). Adaptation to chronic illness. In P. Larsen & I. M. Lubkin (Eds.), *Chronic illness impact and interventions* (7th ed.). Boston: Jones and Bartlett.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer Publishing Company.
- Lazarus, R. S., & Folkman, S. (1987). Transactional theory and research on emotions and coping. *European Journal of Personality*, 1, 141-170.
- Lefcourt, H. M. (2005). Humor. In C. R. Snyder & S. J. Lopez (Eds.), *Handbook of positive psychology* (pp. 619-631). New York: Oxford University Press.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.
- Linley, P. A., & Joseph, S. (2004). *Positive psychology in practice*. New Jersey: John Wiley & Sons, Inc.
- Livneh, H., & Antonak, R. (2005). Psychosocial adaptation to chronic illness and disability: A primer for counsellors. *Journal of Counselling and Development*, 83, 12-20.
- Lopez, S. J., Floyd, R. K., Ulven, J. C., & Snyder, C. R. (2000). Hope therapy: Helping clients build a house of hope. In C. R. Snyder (Ed.), *Handbook of hope: Theory, measures and applications* (pp. 123-166). San Diego, CA: Academic Press.
- Lopez, S. J., & Snyder, C. R. (2003). *Positive psychology assessment: A handbook of models and measures*. Washington: APA.
- Luthar, S. S., Cicchetti, D & Becker, B (2000). The construct of resilience: A critical evaluation and guidelines for future work. *Child Development*, 71(3), 543. 62.
- Lynch, W. F. (1965). *Images of hope: Imagination as healer of the hopeless*. New York: New American.
- Lynn, J. (1997). Transverse Myelitis: Symptoms, causes and diagnosis. Transverse Myelitis Association. Retrieved on 12 Sept 2012 from www.myelitis.org/tm.html

- Lyubomirsky, S. (2001). Why are some people happier than others? The role of cognitive and motivational processes in well-being. *American Psychologist*, 45(3), 239-249.
- Maier, S. F., & Watkins, L. R. (2010). Role of the medial prefrontal cortex in coping and resilience. *Brain Research*, 1355, 52-60.
- Main C. J., & Spanswick C. C. (2000). Pain management: An interdisciplinary approach. *Pain*, 80, 1-13.
- Marcel, G. (1962). *Homo Viator: Introduction to a metaphysic of hope* (as translated by E. Craufurd). New York: Harper & Rowe.
- Marshall, C., & Rossman, G. B. (1995). *Designing qualitative research* (2nd Edition). Thousand Oaks, CA: Sage.
- Marshall, M. N. (1996). Sampling for qualitative research. *Family Practice*, 13(6), 522-525.
- Martin, R. A., & Dobbin, J. P. (1988). Sense of humor, hassles and immunoglobulin A: Evidence for a stress-moderating effect of humour. *International Journal of Psychiatry in Medicine*, 18, 93-105.
- Martin, R. C., & Dahlen, E. R. (2005). Cognitive emotion regulation in the prediction of depression, anxiety, stress and anger. *Personality and Individual Differences*, 39, 1249-1260.
- Martz, E., & Livneh, H. (2007). *Coping with chronic illness and disability – theoretical, empirical and clinical aspects*. New York: Springer science and business.
- Maruta T., Colligan R. C., Malinchoc M., & Offord K. P. (2000). Optimists vs. pessimists: Survival rate among medical patients over a 30-year period. *Mayo Clinic Proceedings*, 75, 140–143.
- Maslow, A. H. (1943). A theory of human motivation. *Psychological Review*, 50(4), 370-96.
- Masten, A. S. (2009). Ordinary magic: Lessons from research on resilience in human development. *Education Canada*, 49 (3), 28. 32.
- Masten, A. S. (2001). Ordinary magic: Resilience processes in development. *American Psychologist*, 56(3), 227-238.
- Masten, A. S., & Reed, M. J. (2005). Resilience in development. In C. R. Snyder & S. J. Lopez (Eds.), *Handbook of Positive Psychology* (pp. 74-88). New York: Oxford University Press.

- McCullough, M. E., & Snyder, C. R. (2000). Classical source of human strength: Revisiting an old home and building a new one. *Journal of Social and Clinical Psychology, 19*, 1-10.
- McCullough, M. E., & Tsang, J. (2004). Measuring religious constructs: A hierarchical approach to construct organisation and scale selection. In C. R. Lopez & S. J. Snyder (Eds.), *Positive psychological assessment: A handbook of models and measures* (pp. 345-360). Washington, DC: American Psychological Association.
- McGee, R. F. (1984). Hope: A factor influencing crisis resolution. *Advances in Nursing Science, 6*(4), 34-44.
- McMillan, J. H., & Schumacher, S. S. (1997). *Research in education: a conceptual introduction*. New York: Longman.
- Melzack, R., & Wall, P. D. (1965). Pain mechanisms: a new theory. *Science Journal, 750*, 971-979.
- Melzack, R. (1996). Gate control theory: on the evolution of pain concepts. *Official Journal of the American Pain Society, 5*, 128-138.
- Menninger, K. (1959). The academic lecture on hope. *American Journal of Psychiatry, 190*, 481-491.
- Merriam, S. B. (1998). *Qualitative research and case study applications in education*. San Francisco: Jossey-Bass Publishers.
- Merskey, N., & Bogduk, N. (1994). *Classification of chronic pain: IASP task force on taxonomy* (2nd Edition). Seattle: IASP Press.
- Meyer, H. P. (2007). Pain management in primary care - current concepts. *South African Pharmaceutical Journal, 74*(6), 18-56.
- Miller, J. (1985). Inspiring hope. *American Journal of Nursing, 85*, 22-25.
- Miller, J., & Powers, M. (1988). Development of an instrument to measure hope. *Nursing Research, 37*, 6-10.
- Miller, J. (1989). Hope inspiring strategies of the critically ill. *Applied Nursing Research, 3*, 23-29.
- Mills, R. C. (1995). *Realizing mental health: Toward a new psychology of resiliency*. New York: Sulzberger & Graham.

- Minagar, A., & Alexander, J. S. (Eds.). (2005). *Inflammatory disorders of the nervous system: pathogenesis, immunology and clinical Management*. New Jersey: Humana Press.
- Mnookin, R. H., Peppet, S. R., & Tulumello, A. S. (2007). The tension between empathy and assertiveness. *Negotiation Journal* 12(3), 217-230.
- Moos, R. H., & Holahan, C. J. (2007). Adaptive tasks and methods of coping with illness and disability. In E. Martz & H. Livneh (2007). *Coping with chronic illness and disability - theoretical, empirical and clinical aspects* (pp. 107-126). New York: Springer science and business.
- Morano, C. (2010). Resilience and coping with trauma: Does gender make a difference?. *Journal of Human Behavior in the Social Environment*, 20(4), 553-568.
- Mowrer, O. H. (1960). *Learning theory and behavior*. New York: Wiley and Sons.
- Murnaghan, D. A. (1992). *The relationship between hope and level of coping in patients with cancer and nurses' perceptions of their patients' level of hope*. (Unpublished master's dissertation.) Dalhousie University, Halifax, Nova Scotia.
- Nakamura, J., & Csikszentmihalyi, M. (2001). Catalytic creativity. *American Psychologist*, 56(4), 337-341.
- Neill, J. (2006). *What is psychological resilience?* Retrieved on 26 June 2006 from <http://www.wilderdom.com/psychology/resilience/PsychologicalResilience.html>
- Nowotny, M. (1989). Assessment of hope in patients with cancer: Development of an instrument. *Oncology Nursing*, 16(1), 57-61.
- Obayuwana, A., & Carter, A. (1982). The anatomy of hope. *Journal of the National Medical Association*, 74, 229-239.
- Ogden, J. (2001). *Health psychology*. Buckingham: Open University Press.
- Owen, D. (1989). Nurses' perspectives on the meaning of hope in patients with cancer: A qualitative study. *Oncology Nursing Forum*, 16, 75-79.
- Pakenham, K. I. (1999). Adjustment to multiple sclerosis: Application of a stress and coping model. *Health Psychology*, 18(4), 383-392.

- Pakenham, K. I. (2007). The nature of benefit finding in multiple sclerosis (MS). *Psychology, Health and Medicine*, 12(2), 190-196.
- Pakenham, K. I., & Cox, S. (2009). The dimensional structure of benefit finding in multiple sclerosis and relations with positive and negative adjustment: A longitudinal study. *Psychology & Health*, 24(4), 373-393.
- Pakenham K. I., Stewart, C. A., & Rogers, A. (1997). The role of coping in adjustment to multiple sclerosis-related adaptive demands. *Psychology, Health & Medicine*, 2(3), 197-211.
- Pargament, K. I. (1997). *The psychology of religion and coping*. New York: Guilford Press.
- Pargament, K. I. (1999). The psychology of religion and spirituality? Yes and no. *The International Journal for the Psychology of Religion*, 9, 3-16.
- Pargament, K. I. (2000a). The bitter and the sweet: An evaluation of the costs and benefits of religiousness. *Psychological Inquiry*, 13, 168-181.
- Pargament, K. I. (2000b). Is religion nothing butō ? Explaining religion versus explaining religion away. *Psychological Inquiry*, 13, 239-244.
- Pargament, K. I., & Hahn, J. (1986). God and the just world: Causal and coping attributions to God in health situations. *Journal for the Scientific Study of Religion*, 25, 193-207.
- Park, A. (2011). Healing the hurt. Finding new ways to treat pain. *Time Magazine*, 177(11), 64-68.
- Park, C. L., & Folkman, S. (1997). Meaning in the context of stress and coping. *Review of General Psychology*, 1(2), 115-144.
- Parker, J. D. A., & Endler N. S. (1992). Coping with coping assessment: a critical review. *European Journal of Personality*, 6, 321. 344.
- Parker, J. N., & Parker, P. M. (2002). *The official patient's sourcebook on transverse myelitis*. San Diego: Icon Health Publications.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.) Newbury Park, CA: Sage Publications, Inc.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd Edition). Thousand Oaks, CA: Sage Publications, Inc.

- Peterson, C. (2006). *A primer in positive psychology*. New York: Oxford University Press.
- Peterson, C. (2009). Positive psychology. *Reclaiming Children and Youth*, 18(2), 5.
- Peterson, C., & Seligman, M. E. P. (2004). *Character strengths and virtues*. New York: Oxford University Press.
- Peterson, C., & Steen, T. A. (2005). Optimistic explanatory style. In C. R. Snyder & S. J. Lopez (Eds.), *Handbook of positive psychology* (pp. 244-256). New York: Oxford University Press.
- Post, S. G. (2005). Altruism, happiness and health: it's good to be good. *International Journal of Behavioral Medicine*, 12(2), 66-77.
- Raleigh, E. D. (1980). An investigation of hope as manifested in the physically ill adult. *Dissertation Abstracts International*, 41, 1313B-1314B (University Microfilms No. 8022786).
- Rapmund, V., & Moore, C. (2000). Women's stories of depression: a constructivist approach. *South African Journal of Psychology*, 30(2), 20-30.
- Ratcliff, D. (2006). *Qualitative research methods*. Retrieved on 18 March 2007 from <http://don.ratcliffs.net/qual/1.htm>
- Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 18(1), 20-23.
- Reisman, J. (1991). *A history of clinical psychology*. UK : Taylor Francis.
- Resnick, S., Warmoth A., & Serlin, I. A. (2001). The humanistic psychology and positive psychology connection: Implications for psychotherapy. *Journal of Humanistic Psychology*, 41, 73-102.
- Reynolds, F. (2000). Managing depression through needlecraft creative activities: A qualitative study. *The Arts in Psychotherapy*, 27 (2), 107-114.

- Robinson, W. H., DiGennaro, C., Hueber, W., Haab, B. B., Kamachi, M., Dean J. D., ...Utz, P. J. (2002). Autoantigen microarrays for multiplex characterization of autoantibody responses. *Nature Medicine* 8, 295-330.
- Rogers, C. R. (1942). *Counseling and psychotherapy*. Boston: Houghton Mifflin.
- Rubenstein, C., & Shaver, P. (1980). Loneliness in two north eastern cities. In J. Hartog, J. R. Audy & Y. A. Cohen (Eds.), *Anatomy of Loneliness* (pp. 319-337). New York: International Universities Press.
- Rutter, M. (2007). Resilience, competence and coping. *Child Abuse & Neglect*, 31(3), 205-209.
- Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development and well-being. *American Psychologist*, 55, 68-78.
- Ryan, R. M., & Deci, E. L. (2001). To be happy or to be self-fulfilled: A review of research on hedonic and eudaimonic well-being. In S. Fiske (Ed.), *Annual Review of Psychology* 52, 141-166.
- Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, 57, 1069. 1081.
- Sahni, V., Garg, D., Garg, S., Agarwal, S. K., & Singh, N. P. (2008). *Unusual complications of heroin abuse: transverse myelitis, rhabdomyolysis, compartment syndrome and ARF*. Department of Internal Medicine, Drexel University College of Medicine, Philadelphia, Pennsylvania, USA.
- Sauer, S. E., Burris, J. L., & Carlson, C. R. (2010). New directions in the management of chronic pain: Self-regulation theory as a model for integrative clinical psychology practice. *Clinical Psychology Review*, 30, 805-814.
- Scheier, M. F., & Carver, C. S. (1992). Effects of optimism on psychological and physical well-being: Theoretical overview and empirical update. *Cognitive Therapy and Research*, 16, 201. 228.
- Scheier, M. F., & Carver, C. S. (1985). Optimism, coping and health: Assessment and implications of generalized outcome expectancies. *Health Psychology*, 4, 219-247.
- Schneider, S. L. (2001). In search of realistic optimism. *American Psychologist*, 56 (3), 250-263.

- Schneider, M. A. (2009). Humor as a coping strategy for adult-child care-givers of individuals with Alzheimer's disease. *Geriatric Nursing*, 30(6), 397-408.
- Schwarzer, R., & Knoll, N. (2004). Positive coping: Mastering demands and searching for meaning. In S. J. Lopez & C. R. Snyder, *Handbook of positive psychological assessment* (chapter 25). Washington, DC: American Psychological Association.
- Schweitzer, A. (1931). *Out of my life and thought: an autobiography*. ("Aus Meinem Leben und Denken", Felix Meiner Verlag, Leipzig, 1931). Johns Hopkins University Press.
- Seligman, M. E. P., & Csikszentmihalyi, M. (2000). Positive psychology: An introduction. *American Psychologist*, 55 (1), 5-14.
- Seligman, M. E. P. (2003). *Authentic happiness. Using the new positive psychology to realize your potential for lasting fulfillment*. London: Nicholas Brealey.
- Shapiro, J., & Shapiro, D. H. (1983). Well-being and relationship. In R. Ealsh & D. H. Shapiro (Ed.), *Beyond Health and Normality Explorations of Exceptional Psychological Well-being*. New York: Van Nostrand Reinhold Co.
- Sheldon, K. M., & King, L. (2001). Why positive psychology is necessary. *American Psychologist*, 56 (3), 216-217.
- Simonton, D. K. (2000). Creativity: cognitive, personal, development and social aspects. *American Psychologist*, 55 (1), 151-158.
- Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, 11, 261. 271.
- Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray and K. Chamberlain (Eds.), *Qualitative Health Psychology: Theories and Methods*, 218. 240. London: Sage.
- Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Methods*. London: Sage.
- Smith J. A. & Osborn M. (2007). Pain as an assault on the self: an interpretative phenomenological analysis. *Psychology & Health*, 22, 517-34.

- Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J. Smith (Ed.), *Qualitative Psychology*. London: Sage.
- Snyder, C. R. (1994). *The psychology of hope: You can get there from here*. New York: Free Press.
- Snyder, C. R., Harris, C. Anderson, J. R., Holleran, S. A., Irving, L. M., Sigmon, S. T. ...Harney, P. (1991). The will and the ways: Development and validation of an individual-differences measure of hope. *Journal of Personality and Social Psychology*, *60*, 570-585.
- Snyder, C. R., Lapointe, A. B., Crowson, J. J., Jr., & Early, S. (1998). Preferences of high- and low-hope people for self-referential input. *Cognition and Emotion*, *12*, 807-823.
- Snyder, C. R., & Lopez, S. J. (2002). *Handbook of positive psychology*. Oxford: Oxford University Press.
- Snyder, C. R., & Lopez, S. J. (2005). *Handbook of positive psychology*. New York: Oxford University Press.
- Snyder, C. R., & McCullough, M. E. (2000). A positive psychology field of dreams: %& you build it, they will comeõ ± *Journal of Social and Clinical Psychology*: *19*(1), 151-160.
- Snyder, C. R., & Pulvers, K. M. (2001). Dr. Seuss, the coping machine and "Oh the places you'll go." In C. R. Snyder (Ed.), *Coping with Stress: Effective People and Processes* (pp. 3-29). Oxford: Oxford University Press.
- Snyder, C. R., Rand, K. L., & Sigmon, D. R. (2002). Hope theory: A member of the positive psychology family. In C. D. Snyder & S. J. Lopez (Eds.), *The handbook of positive psychology* (pp. 257-276). New York, New York: Oxford University Press.
- Somerfield, M. R., & McCrae, R. R. (2000). Stress and coping research. *American Psychologist*, *55*(6), 620-625.
- Spilka, B., Hood, R. W. Jr., & Gorsuch, R. L. (1985). *The psychology of religion: an empirical approach*. NJ, USA: Englewood Cliffs, Prentice-Hall.
- Squire, L., Berg, D., & Bloom F. E. (2008). *Fundamental Neuroscience* (3rd ed.). Waltham Massachusetts: Academic Press.
- Stamford, J. A. (1995). *Descending control of pain*. *British Journal of anaesthesia*, *75*, 217-227.

- Stanley, A. (1978). The lived experience of hope. The isolation of discrete descriptive elements common to the experience of hope in healthy young adults. *Dissertation Abstracts International*, 39(03), 1212-B. (University Microfilms No. 7816899).
- Stone, L. A. (1997). Transverse myelitis. In L. A. Rolak, & Y. Harati (Eds.), *Neuroimmunology for the Clinician*. Boston: Butterworth-Heinemann.
- Stoner, M. H., & Keampher, S. H. (1985). Recalled life expectancy information, phase of illness and hope in Cancer Patients. *Research in Nursing and Health*, 8, 269-274.
- Stöppler M. C., & Shiel W. C. Jr. (2008). Endorphins: Natural pain and stress fighters, *Webster's New World™ Medical Dictionary, 3rd Edition*.
- Stotland, E. (1969). *The psychology of hope*. San Francisco, CA: Jossey-Bass.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage Publications, Inc.
- Strümpfer, D. J. W. (1990). *Salutogenesis: A new paradigm*. *South African Journal of Psychology*, 20(4), 265-276.
- Strümpfer, D. J. W. (1995). The origin of health and strength: From salutogenesis to fortigenesis. *South African Journal of Psychology*, 25(2), 81-89.
- Strümpfer, D. J. W. (2004). *Positive emotions, positive emotionality and their contribution to fortigenic living: a review*. Unpublished Manuscript used by departments of psychology, Universities of Pretoria and Johannesburg, Gauteng.
- Strümpfer, D. J. W. (2005). Standing on the shoulders of giants: Notes on early positive psychology. *South African Journal of Psychology*, 35(1), 21-45.
- Sympson, S. (2000). Rediscovering hope: Understanding and working with survivors of trauma. In C. R. Snyder (Ed.), *Handbook of hope: Theory, measures, & applications* (pp. 285-300). San Diego, CA: Academic.
- Taylor, E. (2001). Positive psychology and humanistic psychology: A reply to Seligman. *Journal of Humanistic Psychology*, 41, 13-29.

- Tugade, M. M., & Fredrickson, B. L. (2002). Positive emotions and emotional intelligence. In L. Feldman Barrett & P. Salovey (Eds.), *The Wisdom of Feelings* (pp. 319-340). New York: Guilford.
- Tugade, M. M., Fredrickson, B. L., & Feldman Barrett, L. (2004). Psychological resilience and positive emotional granularity: Examining the benefits of positive emotions on coping and health. *Journal of Personality*, 72(6), 1161-1190.
- Tugade, M. M., & Fredrickson, B. L. (2004). Resilient individuals use positive emotions to bounce back from negative emotional experiences. *Journal of Personality and Social Psychology*, 86(2), 320-333.
- Turner J. C. (1975), Some current issues in research on social identity and self- categorization theories. In N. Ellemers, R. Spears, & B. Doojse (Eds.), *Social identity: Context, commitment, content* (pp. 6. 34). Oxford: Blackwell.
- Uchino, B. (2004). *Social support and physical health: Understanding the Health consequences of relationships*. New Haven, CT: Yale University Press.
- Van der Knaap, M. S., & Valk, J. (2005). *Magnetic resonance of myelination and myelin disorders*. Birkhäuser, Amazon. De.
- Van Manen, M. (1997). From meaning to method. *Qualitative Health Research*, 7, 345-369.
- Wallis, C. (2005). The right (and wrong) way to treat pain. Time Magazine. Read more:
<http://www.time.com/time/magazine/article/0,9171,1029836,00.html#ixzz1Ht9Ey7tj>
- Wanzer, M. B., Booth-Butterfield, M., & Booth-Butterfield, S. (2005). If we didn't use humor, we'd cry. *Journal of Health Communication*, 10(2), 105-125.
- Waterman, A. S. (1993). Two conceptions of happiness - contrasts of personal expressiveness (eudemonia) and hedonic enjoyment. *Journal of Personality and Social Psychology*, 64, 678-691.
- Weisman, A. D. (1979). *Coping with Cancer*. New York: McGraw-Hill.
- Wertz, Frederick J. (2005). Phenomenological research methods for counseling psychology. *Journal of Counseling Psychology*, Vol 52(2), Apr 2005, 167-177. doi: 10.1037/0022-0167.52.2.167

- Williams, G. (1984). The genesis of chronic illness: Narrative re-construction. *Journal of Sociology of Health and Illness*, 6, 175-200.
- Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. Buckingham: Open University Press.
- Wissing, M. P. (2000). *Wellness: Construct clarification and a framework for future research and practice*. Keynote Address at the 1st South African Wellness Conference, Port Elizabeth.
- Wissing, M. P. (2002). Empirical clarification of the nature of psychological well-being. *The South African Journal of Psychology*, 32(1), 32-44.
- Worthen, V., & Isakson, R. (2010). Hope - The Anchor of the Soul: Cultivating Hope and Positive Expectancy. *Issues in Religion and Psychotherapy*, 33(1), 47-56.
- Worthington, E. L., & Scherer, M. (2004). Forgiveness if an emotion-focused strategy that can reduce health risks and promote health resilience: Theory, review and hypotheses. *Psychology & Health*, 19(3), 385-405.
- Zeidner, M., & Saklofske, D. (1996). Adaptive and maladaptive coping. In M. Ziedner & N. S. Endler (Eds.), *Handbook of coping theory, research, applications* (pp. 505-531). New York: John Wiley & Sons.

Bibliography

(Texts which were used as background material
but not referenced in the thesis.)

- Abbey, A. Andrews, F. M., & Halman, L. J. (1995). Provision and receipt of social support and disregard: What is their impact on the marital quality of infertile and fertile couples? *Journal of Personality and Social Psychology*, *68*, 455-469.
- Acitelli, L. K., & Antonucci, T. C. (1994). Gender differences in the link between marital support and satisfaction in older couples. *Journal of Personality and Social Psychology*, *67*, 688-698.
- Adler, N., & Matthews, K. (1994). Health psychology: Why do some people get sick and some stay well? *Annual Review of Psychology*, *45*, 229-259.
- Aikens, J. E., Fischer, J. S., Namey, M., & Rudick, R. A. (1997). A replicated prospective investigation of life stress, coping and depressive symptoms in multiple sclerosis. *Journal of Behavioral Medicine*, *20*, 433-445.
- Antonovsky, A. (1979). *Health, Stress and Coping*. San Francisco: Jossey-Bass.
- Antonovsky, A., & Sagy, S. (1990). Confronting developmental tasks in the retirement transition. *Gerontology*, *30*, 362-368.
- Antonovsky, A. (1991). In European congress on "Mental health in european families". p. 9
<http://www.angelfire.com/ok/soc/agolem.html>
- Antonovsky, A. (1993). The structure and properties of the sense of coherence scale. *Social Science Medicine*, *36*, 725-733.

- Antonovsky, A. (1993). Complexity, conflict, chaos, coherence, coercion and civility. *Social Science Medicine*, 37, 969-981.
- Arnett, P. A., Higginson, C. I., Voss, W. D., Randolph, J. J., & Grandey, A. A. (2002). Relationship between coping, cognitive dysfunction and depression in multiple sclerosis. *Clinical Neuropsychologist*, 16(3), 341-355.
- Aspenwall, L. G., & Staudinger, U. M. (Eds.). (2003). *A psychology of human strengths: Fundamental questions and future directions for a positive psychology*. Washington, DC: APA Books.
- Averill, J. R., Catlin, J., & Chon, K. K. (1990). *Rules of hope*. New York: Springer-Verlag.
- Bandura, A. (1977). *Social learning theory*. Englewood Cliffs, NJ: Prentice Hall Publishers.
- Barnard, J. (2010). *Promoting happiness: a workbook to help you appreciate and get the most out of your life*. MTC Books.
- Barnett, P. A., & Gotlib, I. H. (1988). Psychosocial functioning and depression: Distinguishing among antecedents, concomitants and consequences. *Psychological Bulletin*, 104, 976-126.
- Bediako, S. M., Lattimer, L., Haywood Jr., C., Ratanawongsa, N., Lanzkron, S., & Beach, M. C. (2010). Religious coping and hospital admissions among adults with sickle cell disease. *Journal of Behavioral Medicine*, 34, 120-127.
- Berg, D., Bloom, F., & Squire, L. (2008). *Fundamental neuroscience* (3rd ed.). Academic Press.
- Bower, J. E. (2007). Cancer-related fatigue: Links with inflammation in cancer patients and survivors. *Brain, Behavior and Immunity* 21, 863-71.

- Brandtstädter, J. (1992). Personal control over development: Implications of self-efficacy. In R. Schwarzer (Ed.), *Self-efficacy: Thought control of action* (pp. 127-145). Washington, DC: Hemisphere.
- Brooks, N. A., & Matson, R. R. (1982). Social-psychological adjustment to multiple sclerosis: A longitudinal study. *Social Science and Medicine*, *16*, 2129-2135.
- Buescher, K. L., Johnston, J. A., Parker, J. C., Smarr, K. L., Buckley, S. P. Anderson, S. K., & Walker, S. E. (1991). Relationship of self-efficacy to pain behavior. *Journal of Rheumatology*, *18*, 968-972.
- Bush, E. G., Rye, M. S., Brant, C. R., Emery, E., Pargament, K. I., & Riessinger, C. A. (1999). Religious coping with chronic pain. *Applied Psychophysiology and Biofeedback*, *24*(4), 249-260.
- Campbell, D. T., & Stanley, J. C. (1966). Experimental and quasi-experimental designs for research on teaching. In N. L. Gage (Ed.), *Handbook of research on teaching*. Chicago: Rand McNally.
- Carels, R. A., & Beaucom, D. H. (1999). Support in marriage: Factors associated with on-line perceptions of support helpfulness. *Journal of Family Psychology*, *13*, 131-144.
- Carver, C., Scheier, M., & Wientraub, J. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*, *56*(2), 267-283.
- Chesney, M. A., Darbes, L., Hoerster, K., Taylor, J., Chambers, D. C., & Anderson, D. E. (2005). Positive emotions: The other hemisphere of behavioral medicine. *International Journal of Behavioral Medicine*, *12*, 50-58
- Ciarrocchi, J. W., & Brelsford, G. M. (2009). Spirituality, religion and substance coping as regulators of emotions and meaning making: Different effects on pain and joy. *Journal of Addictions & Offender Counseling*, *30*, 24-36.

- Coetzee, S. C., & Cilliers, F. (2001). Psychofortology: Explaining coping behaviour in organisations. *The Industrial- Organisational Psychologist*, 38(4), 62-68.
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd edition). Hillsdale, NJ: Erlbaum.
- Crombez, G., Vervaeke, L., Lysens, R., Baeyens, F., & Eelen, P. (1996). Avoidance and confrontation of painful, back-straining movements in chronic back pain patients. *Behavior Modification*, 22, 626-77.
- Cronbach, L. J. (1975, February). Beyond the two disciplines of scientific psychology. *American Psychologist*, 30(2), 116-127.
- Csikszentmihalyi, M. (1993). *The evolving self*. New York: HarperCollins.
- Davis, L. J. (2002). *Bending over backwards: Disability, dismodernism and other difficult positions*. New York: New York University Press.
- De Lange, E. F. (2010), *The fortigenic exploration of psychotherapists' experiences in full-time private practice* (Unpublished doctoral thesis). University of South Africa, Pretoria.
- DeGraff, A. (2002). *Care-givers and personal assistants: How to find, hire and manage the people who help you (or your loved one!)*. Fort Collins, CO: Saratoga Access Publications, Inc.
- Denzin, N. K., & Lincoln, Y. S. (2000). *Handbook of qualitative research* (2nd edition.) Thousand Oaks, California: Sage Publications.
- DeWall, C. N., Baumeister, R. F., Stillman, T. F., & Gailliot, M. T. (2007). Violence restrained: Effects of self-regulatory capacity and its depletion on aggressive behavior. *Journal of Experimental Social Psychology*, 43, 62-76.

- Dewitz, S. (2005). Exploring the relationship between self-efficacy and purpose in life. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 65(10-B), 5450.
- Diener, E. (2000). Subjective well-being: The science of happiness and a proposal for a national index. *American Psychologist*, 55, 346-43.
- Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The satisfaction with life scale. *Journal of Personality Assessment*, 49, 71-75.
- Du Preez, E. (2004). The social construction of counsellor identity in a South African context. Unpublished PhD Thesis, Pretoria: UP.
- Duckworth, A., & Seligman, M. (2005). Self-discipline outdoes IQ in predicting academic performance of adolescents. *Psychological Science*, 16, 939-944.
- Duckworth, A. L., Peterson C., Matthews M. D., & Kelly D. R. (2006). Grit, perseverance and passion for long-term goals. *Journal of Personality and Social Psychology*, 92(6), 1087-101.
- Dufault, K. J., & Martocchio, B. (1985). Hope: Its spheres and dimensions. *Nursing Clinics of North America*, 20, 379-391.
- Durkheim, É. (1963)(1912). *The elementary forms of the religious life*. Translated from the French by Joseph Ward Swain. New York: Collier Books.
- Edward, K., & Warelow, P. (2005). *Journal of the American Psychiatric Nurses Association*, 11(2), 101-102.
- Eklund, V. A., & MacDonald, M. L. (1991). Descriptions of persons with multiple sclerosis, with an emphasis on what is needed from psychologists. *Professional Psychology: Research and Practice*, 22, 277-284.

- Elfström, M. L., Rydén, A., Kreuter, M., Persson, L. O., & Sullivan, M. Linkages between coping and psychological outcome in the spinal cord lesioned: Development of SCL-specific measures. *Spinal Cord*. Retrieved on 13 August 2008 from <http://www.nature.com/sc/index.html>.
- Erikson, E. H. (1963). *Childhood and society* (2nd ed.). New York: W. W. Norton.
- Eriksson M., & Lindström B. (2005). Validity of Antonovsky's sense of coherence scale: A systematic review. *Journal of Epidemiology and Community Health* 59, 460-466.
- Fade, S. (2004). Using interpretative phenomenological analysis for public health nutrition and dietetic research: a practical guide. *Proceedings of the Nutrition Society* 63, 647-653.
- Farina, C. J., Heath, A. K., & Popovich, J. M. (1995). *Hope and hopelessness: Critical clinical constructs*. Thousand Oaks, CA: Sage.
- Fava, G. A., Rafanelli C., Cazzaro, M., Conti S., & Grandi, S. (1998). Well-being therapy. A novel psychotherapeutic approach for residual symptoms of affective disorders. *Psychological Medicine*, 28, 475-480.
- Finkel, E., & Campbell, W. (2001). Self-control and accommodation in close relationships: An interdependence analysis. *Journal of Personality and Social Psychology*, 81, 552-561.
- Finkelstein, V., & French, S. (1993). Towards a psychology of disability. In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers ó enabling environments* (pp. 26-33). London: Sage.
- Finlay, L., & Evans, K (2009). *Relational centred qualitative research for psychotherapists and counsellors: exploring meanings and experience*, Wiley Blackwells Publishing.
- Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science and Medicine*, 45, 1207-1221.

- Fordyce, W. E. (1978). Learning processes in pain. In R. A. Sternbach (Ed.), *The psychology of pain* (pp. 49-72). New York: Raven Press.
- Frank, J. D. (1968). The role of hope in psychotherapy. *International Journal of Psychiatry*, 5, 383-395.
- Frank, J. D. (1975). The faith that heals. *Johns Hopkins Medical Journal*, 137, 127-131.
- Frank, R., Umlauf, R., Wonderlich, S., Askanazi, G., Buclelew, S., & Elliot, T. (1987). Differences in coping styles among persons with spinal cord injury: A cluster-analytic approach. *Journal of Consulting and Clinical Psychology*, 55(5), 727-731.
- Frankl, V. E. (1967). *Psychotherapy and existentialism: Selected papers on logotherapy*. New York: Washington Square Press.
- Frankl, V. E. (1978). *The unheard cry for meaning: Psychotherapy and humanism*. London: Hodder and Stoughton.
- Frankl, V. E. (1988). *The will to meaning: Foundations and applications of logotherapy*. New York: Penguin Books.
- Frazier, P. A., Tix, A. P., & Barnett, C. L. (2003). The relational context of social support: Relationship satisfaction moderates the relations between enacted support and distress. *Personality and Social Psychology Bulletin*, 29, 1133-1146.
- Friedman, H. S., & Di Matteo, M. R. (1984). Interpersonal issues in health care. *Journal of Medicine*, 46, 839-852.
- Gal, R., & Lazarus, R. (1975). The role of activity in anticipation and confronting stressful situations. *Journal of Human Stress*, 1, 4-20.
- Galliot, M., Schmeichel, B., & Baumeister, R. (2006). Self-regulatory processes defend against the threat of death: Effects of self-control depletion and trait self-control on thoughts and fears of dying. *Journal of Personality and Social Psychology*, 91, 49-62.

- Geertz, C. (1966). "Religion as a cultural system." In C. Geertz, *The Interpretation of Cultures: Selected Essays* (pp 87-125). London: Fontana Press.
- Gerhart, K., Weitzenkamp, D., Kennedy, P., Glass, C., & Charlifue, S. (1999). Correlates of stress in long-term spinal cord injury. *Spinal Cord*, 37, 183-190.
- Greeff AP, Vansteenwegen A, & Herbiest T. (2011). Indicators of family resilience after the death of a child. *Omega*, Vol. 63(4) 343-358.
- Grounds, M. (2008). *The relationship between meaning in life and optimism*. (Unpublished master's dissertation.) University of Johannesburg, Johannesburg.
- Groves, M. S., & Muskin, P. R. (2005). Psychological responses to illness. In J. E. Levenson (Ed.), *American psychiatric textbook of psychosomatic medicine* (pp. 67-88). Washington, DC: American Psychiatric Publishing.
- Hagglund, K. J., Haley, W. E., Reveille, J. D., & Alarcon, G. S. (1989). Predicting individual differences in pain and functional impairment among patients with rheumatoid arthritis. *Arthritis Rheumatoid*, 32, 851-857.
- Haythornthwaite, J. A., Menefee, L. A., Heinberg, L. J., & Clark, M. R. (1998). Pain coping strategies predict perceived control over pain. *Pain Journal*, 77, 33639.
- Heron, J. (1996). *Co-operative Inquiry: Research into the human condition*. London: Sage.
- Hinds, P. (1988). Adolescent hopefulness in illness and health. *Advances in Nursing Science*, 10, 79-80.
- Holahan, C. J., & Moos, R. H. (1985). Life stress and health: Personality, coping and family support in stress resistance. *Journal Personality Social Psychology*, 49, 7396747.
- Holahan, C. J., & Moos, R. H. (1991). *Journal of Abnormal Psychology*, 100(1), 31-38.

- Holahan, C. J., Moos, R. H., & Schaeffer, J. A. (1996). Coping, stress resistance and growth: Conceptualizing adaptive functioning. In M. Zeidner & N. S. Endler (Eds.), *Handbook of coping: Theory, research, applications*. Wiley, New York.
- Horgan O, & MacLachlan M. (2004). Psychological adjustment to lower-limb amputation: a review. *Disability Rehabilitation*. 26, 837650.
- House, J. S. (1981). *Work stress and social support*. Reading, MA: Addison-Wesley.
- Howard, K. I., Krause, M. S., Saunders, S. M., & Koptka, S. M. (1997). Trials and tribulations in the meta-analysis of treatment differences: Comment on Wampold et al. (1997). *Psychological Bulletin*, 122, 221-225.
- Huberman, A. M., & Miles, M. B. (2002). *The qualitative researcher's companion*. Thousand Oaks California: Sage Publications.
- Hutchinson, A. K. (2005). *Meaning in life and sense of coherence as predictors of coping among young adults*. (Unpublished master's thesis.) University of Johannesburg, Johannesburg.
- International Association for the Study of Pain, Subcommittee on Taxonomy. (1979). Pain terms: A list with definitions and notes on usage. *Pain* 6, 249.
- Jacob, A., Weinschenker, B. G., McLinskey, N., Krupp, L., Fox, R. J., Wingerchuk, D. M., í Cree, B. A. C. (2008). Treatment of Neuromyelitis Optica With Rituximab. *Arch Neurology*, 65(11), 1443-1448.
- Janesick, V. J. (2000). The choreography of qualitative research design: Minuets, improvisations and crystallization. In N. K. Denzin & Y. S. Lincoln, *Handbook of qualitative research* (2nd Edition). Thousand Oaks, California: Sage Publications.

- Jean, V., Paul, R. H., & Beatty, W. W. (1999). Psychological and neurological predictors of coping patterns by patients with multiple sclerosis. *Journal of clinical psychology, 55*(1) 21-26.
- Jensen, M. P., & Karoly, P. (1991). Control beliefs, coping efforts and adjustment to chronic pain. *Journal of Consulted Clinical Psychology, 59*, 431-438.
- Jensen, M. P., Turner, J. A., & Romano, J. M. (1992). Chronic pain coping measures: Individual versus composite scores. *Pain Journal, 51*, 273-280.
- Joseph, A. S., & Wood, M. (2010). The absence of positive psychological (eudemonic) well-being as a risk factor for depression: A ten year cohort study. *Journal of Affective Disorders, 122*(3), 213-217.
- Kanne, D. W. (2002). Emotional intelligence and the transformational learning journey of 30 senior pastors who participated in leading. Dissertation Abstracts International Section A: *Humanities and Social Sciences, 66*(8-A), 2962.
- Karekla, M., & Constantinou, M. (2010). Religious coping and cancer: Proposing an acceptance and commitment therapy approach. *Cognitive and Behavioral Practice, 17*, 371-381.
- Keefe, F. J., & Williams, D. A. (1990). A comparison of coping strategies in chronic pain patients in different age groups, *Journal Gerontology in Psychological Science. 45* 161-165.
- Keefe, F. J., Kashikar-Zuck, S., Robinson, E., Salley, A., Beaupre, P., Caldwell, D., Baucom, D., & Haythornthwaite, J. (1997). Pain coping strategies that predict patients' and spouses' rating of patients' self-efficacy. *Pain Journal, 73*, 191-199.
- Kerr, D. (2001). Transverse Myelitis. In R. T. Johnson, J. W. Griffin, & J. C. McArthur (Eds.), *Current Therapy in Neurologic Disease*, Sixth edition. Mosby Press.

- Kerr, N. (1977). *Understanding the process of adjustment to disability*. Baltimore, MD: University Park.
- Keyes, C. L. M., & Haidt, J. (2003). *Flourishing: Positive psychology and the life well-lived*. Washington, DC: American Psychological Association.
- Keyes, C. L. M. (2006). Subjective well-being in mental health and human development research worldwide: An introduction. *Social Indicators Research*, 77(1), 1-10.
- King Keenan, E. (2010). Seeing the forest *and* the trees: using dynamic systems theory to understand östress and copingö and ötrauma and resilienceö. *Journal of Human Behavior in the Social Environment*, 20(8), 1038-1060.
- Kirk, J., & Miller, M. L. (1986). *Reliability and validity in qualitative research*. Beverly Hills: Sage Publications.
- Kirkpatrick, Lee. (2005). *Attachment, evolution and the psychology of religion*. New York: The Guilford Press.
- Kobasa, S. C. (1979). Stressful life events, personality and health: An inquiry into hardiness. *Journal of Personality and Social Psychology*, 37, 1-11.
- Kobasa, S. C. (1982). The hardy personality: Toward a social psychology of stress and health. In G. S. Sanders & J. Suls (Eds.), *Social psychology of health and illness* (pp.3-32). Hillsdale, NJ: Erlbaum.
- Koestler, A. (1964). *The act of creation*. New York: MacMillan.
- Krefting, L. (1991). Rigor in qualitative research: the assessment of trustworthiness. *American Journal of Occupational Therapy March 1991* 45(3) 214-222.
- Krohne, H. W. (1993). Attention and avoidance. Two central strategies in coping with aversiveness. In H. W. Krohne (Ed.), *Attention and avoidance* (p. 3-15). Seattle, WA: Hogrefe.

- Kvale, S. (1995). The social construction of validity. *Qualitative Inquiry*, 1(1),19-40.
- Lampropoulos, G. K. (2001). Common processes of change in psychotherapy and seven other social interactions. *British Journal of Guidance and Counselling*, 29, 21-33.
- Langford, C. P. H.; Bowsher, J., Maloney, J. P., & Lillis, P. P. (1997). Social support: a conceptual analysis. *Journal of Advanced Nursing* 25, 956100.
- Larsen, R. (2009), Contributions of positive and negative affect to emotional well-being. *Psychological Topics* 18(2) 247-266.
- Lazarus, R. S. (1991). *Emotion and adaptation*. New York: Oxford University Press.
- Lazarus, R. S. (1966). *Psychological stress and the coping process*. New York: McGraw-Hill.
- Lazarus, R. S., & Folkman, S. (1991). The concept of coping. In A. Monat & R. S. Lazarus (Eds.), *Stress and coping: An anthology* (3rd Edition). New York: Columbia University Press.
- Lefcourt, H. M. (2001). *Humor, the psychology of living buoyantly*. New York: Plenum Publishers.
- Lehman, D. R., Wortman, C. B., & Williams, A. F. (1987). Long-term effects of losing a spouse or child in a motor vehicle crash. *Journal of Personality and Social Psychology*, 52, 218-231.
- Leventhal, H. (1970). Findings and theory in the study of fear communications. *Advances in Experimental Social Psychology*, 5, 119-186.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications, Inc.

- Lindsay, G. (2006b). Experiencing nursing education research: Narrative inquiry and interpretive phenomenology. *Nurse Researcher*, 13(4), 30-47.
- Linley, P. A., & Joseph, S. (2004). *Positive psychology in practice*. New Jersey: John Wiley & Sons, Inc.
- Livneh, H., & Sherwood, A. (1991). Application of personality theories and counselling strategies to clients with physical disabilities. *Journal of Counselling and Development*, 69, 525-538.
- Long, D. D., & Miller, J. (1991). Suicidal tendency and multiple sclerosis. *Health & Social Work*, 16(2), 104-109.
- Lopez, S. J., Snyder, C. R., & Teramoto-Pedrotti, J. (2004). Hope: Many definitions, many measures. In S. J. Lopez & C. R. Snyder (Eds.), *Positive psychological assessment a handbook of models and measures* (pp. 91-107). Washington: American Psychological Association.
- Lopez, S. J., Pedrotti, J. T., & Snyder, C. R. (2004). Hope: Many definitions, many measures. In S. J. Lopez, & C. R. Snyder, *Positive psychological assessment: A handbook of models and measures* (pp. 92-95). Washington, DC: American Psychological Association.
- Lopez, S. J., Snyder, C. R., Magyar-Moe, J. L., Edwards, L. M., Pedrotti, J. T., Ganowski, K., Turner, J. L., & Pressgrove, C. (2004). *Strategies for accentuating hope in positive psychology in practice*. New Jersey: John Wiley & Sons, Inc.
- Lorig, K., Chastain, R. L., Ung, E., Shoor, S., & Holman, H. R. (1989). Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. *Arthritis Rheumatoid*, 32, 37-44.

- Luborsky, L., Rosenthal, R., Diguier, L. Andrusnya, T. P., Berman, J. S., Levitt, J. T. ...Krause E.D. (2002). The dodo verdict is alive and well ó mostly. *Clinical Psychology: Science and Practice*, 9, 2-12.
- MacIntyre, A. (1981). *After virtue: A study in moral theory*. London: Duckworth.
- Maes, S., Leventhal, H., de Ridder, D. T. D., Zeidner, M., Endler, & Norman, S. (1996). *Handbook of coping: Theory, research, applications*. Oxford, Engl.: John Wiley & Sons.
- Martin, R. (2004). Sense of humor. In S. J. Lopez & C. R. Snyder (Eds.), *Positive psychological assessment: A handbook of models and measures* (pp. 314-324). Washington, DC: American Psychological Association.
- McCabe, M. P., & McKern, S. (2002). Quality of life and multiple sclerosis: Comparison between people with multiple sclerosis and people from the general population. *Journal of Clinical Psychology in Medical Settings*, 9(4) 287-295.
- McCabe, M. P., McKern, S., & McDonald, E. (2004). Coping and psychological adjustment among people with multiple sclerosis. *Journal of Psychosomatic Research*, 56(3) 355-361.
- Melzack, R., & Wall, P. D. (1982). *The challenge of pain*. New York: Basic Books.
- Menter, R. R. (1993). Spinal cord injury and aging: Exploring the unknown. *Journal of the American Paraplegia Society*, 16(4) 179-189.
- Miller, J. F. (2000). *Coping with chronic illness: Overcoming powerlessness* (3rd Edition). New York: FA Davis.
- Mischel, M., Hostetter, T., King, B., & Graham, V. (1984). Predictors of psychosocial adjustment in patients newly diagnosed with genealogical cancer. *Cancer Nursing*, 7, 291-299.

- Mohr, D. C., Goodkin, D. E., Gatto, N., & Van der Wende, J. (1997). Depression, coping and level of neurological impairment in multiple sclerosis. *Multiple Sclerosis Journal*, 3, 254-258.
- Mohr, D. C., Dick, L. P., Russo, D., Finn, J., & Boudewyn, A. C. (1999). The psychosocial impact of multiple sclerosis: Exploring the patient's perspective. *Health Psychology* 18(4), 376-382.
- Mohr, D. C., Goodkin, D. E., Nelson, S., Cox, D., & Weiner, M. (2002). Moderating effects of coping on the relationship between stress and the development of new brain lesions in multiple sclerosis. *Psychosomatic Medicine*, 64(5), 803-809.
- Mohr, D. C., Hart, S. L., Julian, L., Catledge, C., Honos-Webb, L., Vella, L., & Tasch, E. T. (2005). Telephone-administered psychotherapy for depression. *Archives of General Psychiatry*, 62(9), 1007-1014.
- Moos, R. H., Schaefer, J. A. (1984). The crisis of physical illness: An overview and conceptual approach. In R. H. Moos (Ed.), *Coping with physical illness: New perspectives*. New York: Plenum Press.
- Morano, C. (2010). Resilience and coping with trauma: Does gender make a difference?. *Journal of Human Behavior in the Social Environment*, 20(4), 553-568.
- Murberg T. A., & Bru E. (2001). Coping and mortality among patients with congestive heart failure. *International Journal of Behavioral Medicine* 8(1), 66-79.
- Nosek, M., & Hughes, R. (2001). Psychospiritual aspects of sense of self in women with physical disabilities. *Journal of Rehabilitation*, 67(1), 20-37.
- O'Brien, M. T. (1993). Multiple sclerosis: The relationship among self-esteem, social support and coping behavior. *Applied Nursing Research*, 6, 54-63.
- O'Brien, R. A., Wineman, N. M., & Nealon, N. R. (1995). Correlates of the caregiving process in multiple sclerosis. *Scholarly Inquiry for Nursing Practice*, 9(4), 323-338.

- O'Brien, T. B., & DeLongis, A. (1996). The interactional context of problem-, emotion- and association-focused coping: the role of the big five personality factors. *Journal of Personality, 64*, 775-813.
- Pakenham, K. I. (1998). Couple coping and adjustment to multiple sclerosis in care receiver-carer dyads. *Family Relations, 47*, 269-277.
- Pakenham, K. I. (2001). Coping with multiple sclerosis: Development of a measure. *Psychology, Health, & Medicine, 6*(4), 411-428.
- Pakenham, K. I. (2001a). Application of a stress and coping model to caregiving in multiple sclerosis. *Psychology, Health & Medicine, 6*(1), 13-27.
- Pakenham, K. I. (2005). Benefit finding in multiple sclerosis and associations with positive and negative outcomes. *Health Psychology, 24*(2), 123-132.
- Pakenham, K. I. (2005). Relations between coping and positive and negative outcomes in careers of persons with multiple sclerosis (MS). *Journal of Clinical Psychology in Medical Settings, 12*(1), 25-38.
- Pakenham K. I., Dadds, M. R., & Terry, D. J. (1994). Relationship between adjustment to HIV and both social support and coping. *Journal of Consulting and Clinical Psychology, 62*(6), 1194-1203.
- Pakenham, K. I., & Rinaldis, M. (2001). The role of illness, resources, appraisal and coping strategies in adjustment to HIV/AIDS: The direct and buffering effects. *Journal of Behavioral Medicine, 24*(3), 259-279.
- Pasch, L. A., Bradbury, T. N., & Sullivan, K. T. (1997). Social support in marriage: An analysis of intraindividual and interpersonal components. In G. R. Pierce, B. Lakey, I. G. Sarason & B. R. Sarason (Eds.), *Source Book of Social Support and Personality* (pp 229-256). New York: Plenum.

- Penley, J. A., & Tomaka, J. (2002). Associations among the Big Five, emotional responses and coping with acute stress. *Personality and Individual Differences*, 32, 1215-1228.
- Peterson, C., Park, N., & Seligman, M. E. (2005b). Orientations to happiness and life satisfaction: The full life versus the empty life. *Journal of Happiness Studies*, 6, 25-41.
- Phillips III, R. E., & Stein, C. H. (2007). God's will, God's punishment, or God's limitations? religious coping strategies reported by young adults with serious mental illness. *Journal of Clinical Psychology*, 63(3), 529-540.
- Phillips, D. C. (1990). Subjectivity and objectivity: An objective inquiry. In E. W. Eisner and A. Peshkin (Eds.), *Qualitative inquiry in education: The continuing debate* (pp. 19-37). New York: Teachers College Press.
- Piedmont, R. (1998). *The revised NEO personality inventory: Clinical and research applications*. New York: Plenum.
- Piedmont, R. (2001). Spiritual transcendence and the scientific study of spirituality. *Journal of Rehabilitation*, 67(1), 4-14.
- Rand, K. L., Cripe, L. D., Monahan, P. O., Tong, Y., Schmidt, K., & Rawl, S. M. (2011). Illness appraisal, religious coping and psychological responses in men with advanced cancer. *Support care in cancer*. Springer.
- Rejeski, W. J., Craven, T., Ettinger, W. H. Jr., McFarlane, M., & Shumaker, S. (1996). Self-efficacy and pain in disability with osteoarthritis of the knee, *Journal Gerontology in Psychological Science.*, 51B pp.24-29.
- Reker, G. T., & Wong, P. T. (1988). Aging as an individual process: Toward a theory of personal meaning. In J. E. Birren, & V. L. Bengston (Eds.), *Emergent theories of Aging* (pp.214-246). New York: Springer.
- Rogers, C. R. (1980). *A way of being*. USA: Houghton Mifflin Co.

- Rothbaum, F., Weisz, J. R., & Snyder, S. (1982). Changing the world and changing the self: A two-process model of perceived control. *Journal of Personality and Social Psychology*, 42, 5-37.
- Ryff, C. D., & Singer, B. H. (1996). Psychological well-being: meaning, measurement and implications for psychotherapy research. *Psychother Psychosom* (65), 14-23.
- Sarason, I. G., & Sarason, B. R. (Eds.), *Source book of social support and personality* (pp 229-256). New York: Plenum.
- Savolaine, & Granello, P. F. (2002). The function of meaning and purpose for individual wellness. *Journal of Humanistic Counselling, Education and Development*, 41, 178-189.
- Scharloo, M., Kaptein, A. A., Weinman, J., J. M Hazes, bJ. M., L. N. A Willems, L. N. A., W Bergman, W., & H. G. M Rooijmans, H. G. M. (1998). Illness perceptions, coping and functioning in patients with rheumatoid arthritis, chronic obstructive pulmonary disease and psoriasis. *Journal of Psychosomatic Research*, 44, 573-585.
- Schmidt-Hidding, W. (Ed.). (1963). *Europaieche Schlüsselwörter: Vol. 1. Humor und Witz*. Munich, Germany: Huber.
- Schwarz, S., Knauth, M., Mohr, A, Wildemann, B., Sommer, C., & Storch-Hagenlocher, B. (2001). Acute disseminated encephalomyelitis (ADEM). *Nervenarzt*, 72(4), 241-254.
- Schwarzer, R., & Schwarzer, C. (1996). A critical survey of coping instruments. In M. Zeidner & N. S. Endler (Eds.), *Handbook of coping: Theory, research and applications* (pp. 107-132). New York: Wiley.
- Scott, K. K. (1998). The 'psychological emergency' of new onset physical disability and deformity. *Jacksonville Medicine*, 48(5). University of Florida, FL, USA.

- Scott, T. F., Frohman, E. M., De Seze, J., Gronseth, G. S., & Weinschenker, B. G. (2011). Evidence-based guideline: Clinical evaluation and treatment of transverse myelitis. *Electronic journal of Medscape Medical News Neurology*, 77(24), 2128-2134. doi: 10.1212/WNL.0b013e31823dc535
- Seligman, M. E. P., & Csikszentmihalyi M. (2002). Positive psychology: An introduction, *American Psychologist Journal*, 55(1), 5-14.
- Seligman, M. E. P., Parks, A., & Steen, T. (2004). A balanced psychology and a full life: The royal society, philosophical transactions. *Biological Sciences*, 359, 1379-1381.
- Seligman, M. E. P., Steen, T., Park, N., & Peterson, C. (2005). Positive psychology progress: Empirical validation of interventions. *American Psychologist*, 60(5), 410-421.
- Seligman, M. E. P. (2008). Positive health. *Applied Psychology: An International Review*, 57, 3-18.
- Shaw, R. L. (2001). Why use interpretative phenomenological analysis in Health Psychology? *Health Psychology Update*, 10(4), 48-52.
- Shek, T. L. (1992). Meaning in life and psychological well-being: An empirical study using the Chinese version of the Purpose in life questionnaire. *Journal of Genetic Psychology*, 153(2), 384-392.
- Shoda, Y., Mischel, W., & Peake, P. (1990). Predicting adolescent cognitive and selfregulatory competencies from preschool delay of gratification: Identifying diagnostic conditions. *Developmental Psychology*, 26, 978-986.
- Siegel, K. anderman S. J., & Schrimshaw, E. W. (2001). Religion and coping with health-related stress, *Psychology & Health*, 16:6, 631-653.
- Skrabski, A. (2005). Life meaning: An important correlate of health in the Hungarian population. *International Journal of Behavioural Medicine*, 12(2), 78-85.

- Smart, J. (2001). *Disability, society and the individual*. Austin, TX: Pro-ed.
- Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health, 11*, 261-271.
- Snyder, C. R., Hoza, B., Pelham, W. E., Rapoff, M., Ware, L., & Danovsky, M.. (1997). The development and validation of the Children Hope Scale. *Journal of Pediatric Psychology, 22*, 399-421.
- Snyder, C. R. (1999). *Coping: The psychology of what works*. New York: Oxford University Press.
- Snyder, C. R., Ilardi, S., Cheavens, J., Michael, S. T., Yamhure, L., & Sympson, S. (2000). The role of hope in cognitive behavior therapies. *Cognitive Therapy and Research, 24*, 747-762.
- Snyder, C. R., Ilardi, S., Michael, S. T., & Cheavens, J. (2000). Hope theory: Updating a common process for psychological change. In C. R. Snyder & R. E. Ingram (Eds.), *Handbook of psychological change: Psychotherapy processes and practices for the 21st century* (pp. 128-153) New York: Wiley.
- Snyder, C. R., & Lopez, S. J. (2006). Classifications and measures of human strengths and positive outcomes. In C. R. Snyder & S. J. Lopez (Eds.), *Positive psychology: The scientific and practical explorations of human strengths* (pp. 51-77). Thousand Oaks, CA: Sage Publications.
- Sorg, P. J., & Edmands, T. A. (1993). Prediction of pain in patients with chronic low back pain: Effects of inaccurate prediction and pain-related anxiety. *Behaviour Research and Therapy, 31*, 647-652.
- Staiger, P. K., Melville, F., Hides, L., Kambouropoulos, N., & Lubman, D. I. (2008). Can emotion-focused coping help explain the link between posttraumatic stress disorder severity and triggers for substance use in young adults? *Journal of Substance Abuse Treatment, 36*(2), 220-226.

- Stake, R. E. (1978, February). *The case study method in social inquiry*. *Educational Researcher*, 7(2), 5-8.
- Stiker, H. J. (1982). *A history of disability*. Ann Arbor: University of Michigan Press.
- Stivers, C. (2008). The ontology of hope in dark times. *Administrative Theory & Praxis*, 30(2) 2256239.
- Sullivan, H. (1953). *The interpersonal theory of psychiatry*. New York: Norton Yalom, I. D. (1995).
- Sullivan, H. (1953). *The theory and practice of group psychotherapy (4th Ed.)*. New York: Basic Books.
- Tangney, J., Baumeister, R., & Boone, A. (2004). High self-control predicts good adjustment, less pathology, better grades and interpersonal success. *Journal of Personality and Social Psychology*, 72, 271-322.
- Taylor, C. (1989). *Sources of the self the making of modern identity*. Cambridge: Cambridge University Press.
- Taylor, S. E. (2011). Social support: A review. In M. S. Friedman, *The Handbook of Health Psychology*. New York, NY: Oxford University Press.
- Taylor, S. E., Kemeny, M. E., Reed, G. M., Bower, J. E., & Gruenewald, T. L. (2000). Psychological resources, positive illusions and health. *American Psychologist*, 55, 99-109.
- Taylor, S. E., Lichtman, R R., & Wood, J. V. (1984). Attributions, beliefs about control and adjustment to breast cancer. *Journal of Personality and Social Psychology*, 46, 489-502.
- Terre Blanche, M., & Durrheim, K. (Eds.). (1999). *Research in practice: applied methods for the social sciences*. Cape Town: UCT Press.

- Terre Blanche, M., Kelly, K., & Durrheim, K. (2006). In M. Terre Blanche, K. Durheim, & D. Painter (Eds.), *Research in practice applied methods for the social sciences* (pp. 272-284). Cape Town: Paarl Print.
- Tilden, V. P., & Weinert, S. C. (1987). Social support and the chronically ill individual. *Nursing Clinics of North America* 22 (3), 613-620.
- Trieschmann, R. (1987). *Aging with a disability*. New York: Demos.
- Turk, D. C., Meichenbaum, D., & Genest, M. (1983). *Pain and behavioral medicine: A cognitive-behavioral approach*. Guilford Press, New York.
- Turner, J., & Clancy, S. (1986). Strategies for coping with chronic low back pain: Relationship to pain and disability. *Pain Journal*, 24, 355-364.
- Vash, C. (1981). *The psychology of disability* (1st Edition). New York: Springer Publishing Company, Inc.
- Vash, C. (1994). *Personality and adversity: Psychospiritual aspects of rehabilitation*. New York: Springer Publishing Company, Inc.
- Vash, C., & Crewe, N. (2004). *Psychology of disability* (2nd Edition). New York: Springer Publishing Company.
- Viljoen, G. A. (2008). Short notes on social constructionism as a research approach in psychology. Unpublished Article, Pretoria: UP.
- Wanzer, M. B., Sparks, L., & Frymier, A. B. (2009). Humorous communication within the lives of older adults.: The relationships among humor, age and life satisfaction. *Health Communication*, 24(2), 128-136.

- Warren, S., Warren, K. G., & Cockerill, R. (1991). Emotional stress and coping in multiplesclerosis (MS) exacerbations. *Journal of Psychosomatic Research*, 35,1, 37-47.
- Waterman, A. S. (2007). Introduction to the special issue: Psychosocial identity and well-Being. *Identity*, 7(4), 263-264.
- Watermeyer, B. P. (2009). *Conceptualising psycho-emotional aspects of disablism discrimination and impairment: Towards a psychoanalytically informed disability studies*. (Unpublished doctoral thesis.) Stellenbosch University, Stellenbosch.
- Whiteneck, G., Charlifue, S., Gerhart, K., Lammertse, D., Manley, & S., Menter, R. (1993). *Aging with spinal cord injury*. New York: Demos.
- Whiteneck, G., Mead, M., Dijkers, M., Tate, D., Bushnik, T., & Forchheimer, M. (2004). Environmental factors and their role in participation and life satisfaction after spinal cord injury. *Archives of Physical and Medical Rehabilitation*, 85, 1793-1803.
- Wortman, C. B., Silver, R. C., & Kessler, R. C. (1993). The meaning of loss and adjustment to bereavement. *Handbook of Bereavement: Theory, Research and Intervention*. (pp. 349 ó 366.) New York: Cambridge University Press.
- Wright, B. A. (1983). *Physical disability: A psychosocial approach* (2nd Edition). New York: Harper & Row.
- Yalom, I. D. (1980). *Existential psychotherapy*. New York: Basic Books.
- Yalom, I. D. (1995). *The theory and practice of group psychotherapy*. New York: Basic Books.
- Yi-Frazier, J. P., Smith, R. E., Vitaliono, P. P., Yi, J. C., Mai, S., Hillman, H., & Weinger, K. (2010). A person-focused analysis of resilience resources and coping in patients with diabetes. *Stress and health*, 26, 51-60.

Yrieschmann, R. (1980). *Spinal cord injuries: Psychological, social and vocational rehabilitation*. New York: Pergamon Press.

Zautra, A. J., & Manne, S. L. (1992). Coping with rheumatoid arthritis: A review of a decade of research. *Annual Behavioral Medicine*, 14, 31-39.

Zika, S., & Chamberlain, K. (1992). On the relation between meaning and psychological well-being. *British Journal of Psychology*, 83, 133-145.

Zingale, N., & Hummel, R. (2008). Disturbance, coping and innovation: A phenomenology of terror. *Administrative Theory & Praxis* 30(2), 207-224.

Annexure A

Alet Uys' case study: 2000

Alet Uys has TM and is a member of the TMA. She is a 13 year old living in Pretoria South Africa. Alet has conducted research and wrote a case study which has been published by MedPharm's journal, The Medical Journal. Douw Greeff, MD, the Managing Editor of Geneeskunde/The Medicine Journal, has granted us permission to publish Alet's paper about TM. According to Dr. Greeff, Alet is the youngest person to ever publish in The Medical Journal.

Alet's research and paper were exhibited at the Gauteng Provincial Exposition. She received a gold medal for her work and received an invitation to participate in the National Science Exposition. She also received a certificate of achievement from The Centre for Schools of Quality AFRICA for excellence in Medical Research. The Centre has trustees in the United States, Turkey, China and South Africa. Alet has received the AVENTIS First Prize, for outstanding achievement in medical science.

No less than seven doctors in various branches of medicine visited her stand during the Gauteng Provincial Exposition. The doctors asked her many questions about her research and paper. She dealt with the learned men in a very calm and confident manner, as she was so sure of her facts.

The National Exposition, held in October 2002, is a Youth Science Competition and the most prestigious competition of its kind in Africa. No less than 400 schools participated in the Provincial Exposition; whilst 450 schools participated with 700 projects at the National Exposition. Alet received the gold medal at the National Exposition for the best project in the category, primary school medical sciences. Alet will have the opportunity to exhibit her project in Moscow next year.

Alet's ultimate goal is to go to medical school and to become a neurologist.

Alet Uys's article has been published in Afrikaans in the 2002 July issue of Geneeskunde/The Medicine Journal: Uys A. Transverse Myelitis. Case Study. (Afr) Geneeskunde 2002;43(July)(6):47-50 (ISSN 0016-643X) The article is also available on the Geneeskunde/The Medicine Journal website www.medpharm.co.za.

The following article is a direct translation of the Afrikaans article as published.

I am a 13 year old, grade seven pupil and currently headgirl at Lynnwood Primary school (an Afrikaans school in Pretoria, South Africa). My experience with Transverse myelitis at the age of 11 motivated me to do research on this topic for our school's grade 6 and 7 science expo.

My goal with this research is to improve awareness about Transverse myelitis, especially among medical students and qualified doctors, as the disease is very rare, information in medical literature does not always provide all the answers and the disease can only be cured if it is diagnosed and treated very early.

Two thirds of all Transverse myelitis sufferers do not recover completely; I am very fortunate and grateful to be one of the patients in the world who recovered completely from this disease because of early diagnosis. My research is a way through which I also want to reflect my appreciation for regaining my health.

My work is dedicated to dr Joe Terblanche (Neurologist at Unitas hospital, Centurion, South Africa) who helped me and motivated me to progress, step by step, to where I am today.

My experience with Transverse myelitis started on 2 October 2000. I felt pain from deep within my upper legs and the sensation of a tight band around my waist. The constant and terrible pain kept me awake at night and I felt very sick.

Tuesday October 03: I went to see my family doctor. He drew some blood and suggested that my condition was caused by growing pains. When we phoned him the following day for the results, we were told that the blood got 'lost' and again the doctor said that my condition was only caused by growing pains.

Thursday October 05: My parents decided to take me to an orthopedic surgeon who confirmed that my condition was probably due to 'growing pains' and he prescribed Voltaren gel, which he believed would help to relieve the pain. I was also told to go for an isotope scan the following day in order to confirm the diagnosis.

Friday October 06: The Voltaren gel did not relieve my pain. I went for the isotope scan and the results indicated that everything was fine. My parents and I found it hard to believe that growing pains could be so constant and bad, causing me to wake up time and again during the night.

Sunday evening October 08: I fell out of bed when I tried to get up to go to the bathroom. My parents phoned the orthopedic surgeon at his home and informed him about the weakening condition of my legs. We were told to visit his rooms the following day; when he realized that my problem was not of an orthopedic nature, but neurological, I was immediately referred to a neurologist for a complete neurological examination.

Monday morning October 09: I was finally admitted to hospital with the diagnosis of acute Transverse myelitis and accompanying minor bladder complaints.

Transverse myelitis is a very rare neurological disease that affects one out of a million people each year. The patient's autoimmunes system mistakes the myelin sheath of the spinal cord for intruders and attack the sheaths, causing inflammation of the spinal cord.

Autoimmune diseases are the result of antibodies or T cells that attack molecules, cells, or tissues of the organism that produce them; the following process occurs:

When a germ enters a person's bloodstream, white blood cells are activated to arrest

(via phagocytosis) and transport the germ to the closest lymph node. The lymph node then produces T cells and antibodies to attack and destroy the germ. The antibodies attack the person's tissues by mistake, because certain proteins of the person's tissues resemble the protein covers of the germ.

In the case of Transverse myelitis, the antibodies attack the nerve tissues located in the person's spinal cord. The person's own antibodies become a greater danger than the original germ itself, because the antibodies do not only attack and destroy the original germ, but also the person's own tissues (spinal cord nerves). Messages between central and peripheral nerves are interrupted because of myelin damage caused by the antibodies and the person becomes sick. The condition may deteriorate and progress to paralysis if the disease is not treated promptly, because the antibodies will damage the nerve cells permanently and the person will lose complete function of the bodily areas supplied by these nerves e.g., loss of function of legs and bladder.

Speedy and timely administration of high intravenous doses of cortisone decrease inflammation and swelling of the spinal cord by suppressing the patient's immune response, providing the possibility of less structural tissue damage incurred to nerve cells and a greater chance for recovery.

Autoimmune disease in itself is not rare; Multiple sclerosis, rheumatoid arthritis, SLE, rheumatic fever and nephritis in children are all examples of autoimmune diseases. Transverse myelitis is however a rare way in which autoimmune disease presents. In this instance the antibodies specifically attack the spinal cord tissues.

The myelin sheaths of the nerves become damaged or destroyed at the point of inflammation. This prevents communication between peripheral and central nerves, causing various degrees of motoric and sensoric dysfunction.

Characteristically, the clinical picture presents on both sides of the body, below the spinal cord area affected by the disease. This occurs because the disease process involves the complete width of the spinal cord.

Transverse myelitis may be acute or sub-acute. During an acute attack, the disease develops over a period of a few hours or days. The clinical picture of a sub-acute attack may develop over a period of 1 to 2 weeks.

Early symptoms may include sudden low back pain, loss of muscle power, paresthesia in the toes and feet (within the first few hours up to several weeks), pain in the legs and sensoric loss with partial or total motoric paralysis. Loss of sphincter function may also occur (loss of bladder control is common).

Other symptoms and signs include muscle spasms, poor appetite, headache, fever, a general feeling of discomfort and hyperesthesia during changing weather conditions. Some patients may also experience respiratory problems, depending on the level of spinal cord damage.

Most people only experience one episode of *Transverse myelitis in a lifetime*.

Children and adults, both male and female, may present with *Transverse myelitis*. At present, there is no proof of any hereditary predisposition. All races and families are therefore vulnerable. The highest incidence is found amongst age groups 10 to 19 and 30 to 39 years.

The four classic characteristics of *Transverse myelitis* are

- Varying degrees of motoric loss in arms and legs
- Pain (the most prominent symptom), especially in the lower back, as well as sharp shooting pains in the leg
- Sensoric changes
- Loss of bladder control

Most patients experience various degrees of weakness in their legs. Patients may stumble or drag one foot when they try to walk. They may also experience a sensation where one or both legs feel heavier than normal. Total motoric paralysis may follow as the disease progresses, confining the patient to a wheelchair.

Although some patients recover completely, the majority suffer permanent damage to their spinal cords, causing considerable morbidity in their daily lives.

The extent of pathological dysfunction to areas of the body relates directly to the level of the segment affected in the spinal cord.

The results of my tests indicated that I had an absolute motoric level at T10 and a strength grading of 1/5 in my left leg and 2/5 in my right leg. Other tests included a MRI scan and later that week a Lumbar puncture. Both investigations were indicative of problems.

The diagnosis for *Transverse myelitis* is reached by obtaining a complete medical history and performing a complete neurological examination.

Special investigations that are valuable in assisting to make the diagnosis include, MRI (magnetic resonance imaging) scan of the spinal cord; Myelography (contrast medium is injected into the subarachnoid space and X-rays are then obtained); Hematological (blood) tests for HIV status and vitamin B12 levels; CSF (cerebrospinal fluid) analysis to exclude high protein levels and a high white cell count.

Spinal cord injuries caused by trauma, tumors or abscesses and shortages of vitamin B12 need to be excluded as possible causes for the symptoms.

Idiopathic *Transverse myelitis* is diagnosed when no specific cause can be identified.

I was started on treatment with Soli-Medrol, 500mg per day for 5 days and my condition improved dramatically.

The treatment focus is mainly geared towards providing the patient with symptomatic relief (the degree of neurological dysfunction may have an effect on the severity of symptoms experienced by the patient); Treatment includes

- Corticosteroid therapy, which is the primary form of treatment during the first weeks of the disease. It decreases inflammation and swelling of the spinal

cord and it also suppresses the patient's immune response, but it does not alter the course of the disease

- Relief of pain, on an as-needed basis
- Bed rest during the initial phase of the disease
- The monitoring of vital signs, especially in patients with respiratory problems
- Expectant observation
- A multi-disciplinary approach by a team consisting of a neurologist, specialist physician, hematologist, microbiologist and nursing staff
- Physiotherapy, which plays a very important role during the recovery phase, should focus on strengthening of muscles and improvement of coordination and general movement.

After my treatment, I received physiotherapy for about 2 months. I had to learn to walk again and had to do exercises to develop and regain my balance and strength. The sensation in my body and limbs also started to return and I made very good progress.

Sunday, October 15: The cortisone treatment was stopped and that morning, the same pain of the previous week returned. I was re-admitted to hospital at about 7am and treated with a three-day course of cortisone.

At this stage the doctor decided to start treatment for Bilharzia (a chronic condition that I was diagnosed with during all the special investigations that occurred) for which I received Biltricide, 1200mg once that evening and 600mg the following morning.

October 19: I felt healthy in general and was discharged from hospital. I continued treatment with Prednisone 60mg per day for four days, which was reduced by 5mg every day thereafter, Slow K 1 to 2 times per day, Calcium Sandoz 1 per day and Losec.

The neurologist explained that my autoimmune system over-reacted against another type of infection or virus and attacked my own spinal cord. No other causes could be

found. Because of all this I could not attend the last quarter of school or write my exams.

At present there is little known about the possible etiological factors that may cause Transverse myelitis to occur. The condition mostly results after viral infections, followed by an abnormal immune reaction or it may also occur as a result of insufficient blood supply to certain segments of the spinal cord. Infective agents that may play a role include chicken-pox (*Varicella*), shingles (*Herpes simplex*), flu virus, rubella (German measles) Hepatitis A and rubeola (Measles). Other causes may include bacterial infections of the skin, middle ear and respiratory tract.

It may also occur as a complication of vaccination against e.g., rabies or chicken-pox.

When *Transverse myelitis* follows an infection, the secondary immune response causes more damage to the spinal cord than the primary viral or bacterial infection. The secondary immune response (autoimmune reaction) is considered to be the main cause of the symptoms, resulting in the clinical picture of *Transverse myelitis*.

Recovery from *Transverse myelitis* starts within 2 to 12 weeks after the onset of the disease. It may however prevail for up to two years. It is very unlikely that a patient will recover if there is no improvement within the first 3 to 6 months. One third of patients with *Transverse myelitis* recover completely or partially i.e., they can walk again and are able to maintain bladder control. Another third show moderate recovery with permanent areas of sensoric deficit on the skin, have problems with bladder control and present with spastic movements. The last third do not recover and remain paralyzed and confined to a wheelchair.

Early diagnosis and treatment with corticosteroids mean less damage to the myelin, an improved prognosis and a better chance of recovery.

It is my wish that more people in the medical profession (especially family doctors) will in future be able to recognize Transverse myelitis in its early stages so that the patient can be referred to a neurologist as soon as possible for immediate treatment.

Annexure B

Glossary of medical terms

Antigen	Any substance capable of inducing a specific immune response
Apoptosis	The self destruction of cells
Autonomic dysfunction	Dysfunction of the autonomic nervous system
Axons	An extension of a nerve cell that conducts impulses away from the cell
Bacterial abscess	An enclosed collection of liquefied tissue, known as pus, somewhere in the body pertaining to or caused by bacteria
Biopsy	Removal and examination, usually microscopic, of tissue from the living body, performed to establish a precise diagnosis
Central nervous system (CNS)	Part of the nervous system consisting of the brain, cranial nerves and spinal cord. The brain is the centre of higher processes, such as thought and emotion and is responsible for the coordination and control of bodily activities and the interpretation of information from the senses. The cranial nerves and spinal cord link the brain to the peripheral nervous system, i.e. the nerves present in the rest of body
Cervical level	Relating to the top part of the spine that is composed of the seven vertebrae of the neck and the discs that separate them
Circulatory	Pertaining to circulation, particularly that of the blood
Coxsackievirus	Any of a group of enteroviruses that produces a disease in humans characterised by fever and rash. Coxsackieviruses are named for the town in upstate New York where they were first identified

Cyclophosphamide	A highly toxic, immunosuppressive drug, used in the treatment of Hodgkin's disease, lymphoma and certain other forms of cancer, such as leukaemia and breast cancer
Cytokine	A general term for non antibody proteins released by a specific type of cell as part of the body's immune response. Cytokines are proteins that can damage the nervous system.
Cytomegalovirus	Any of a group of highly host specific herpes viruses, infecting humans, monkeys and rodents, producing unique large cells with intranuclear inclusions; the virus can cause a variety of clinical syndromes, collectively known as cytomegalic inclusion disease, although most infections are mild or subclinical.
Demyelination	The destruction of the protective myelin sheath that surrounds nerve fibres, resulting in the loss of function of those nerves
Dysesthesias	An unpleasant abnormal sensation, whether spontaneous or evoked
Echovirus	Any of a number of retroviruses inhabiting the gastrointestinal tract and associated with various diseases, such as viral meningitis, mild respiratory infections and severe diarrhoea in newborns
Enteroviruses	Viruses, which live in the gastrointestinal tract. Coxsackie viruses are viruses, which cause hand-foot-mouth disease and are enteroviruses
Epstein-Barr virus	A herpes virus that is also associated with various types of human cancers
Guillain-Barré syndrome	Guillain-Barré syndrome (GBS) causes progressive muscle weakness and paralysis (the complete inability to use a particular muscle or muscle group), which develops over days or up to four weeks and lasts several weeks or even months
Herniated disc	Material between spinal vertebrae, which provides a cushion-like support against shock, protruding like a hernia; enclosed in a hernia

Herpes simplex	<p>A recurrent viral disease that is caused by herpesvirus type 1 and is marked by fluid containing vesicles (cold sore) in the mouth, on the lips or face.</p> <p>A recurrent viral disease that is caused by herpesvirus type 2 and is marked by fluid-containing vesicles on the genitals.</p>
Herpes zoster	An infection caused by activation of the latent varicella zoster virus along a nerve pathway. Symptoms include painful blisters and red skin eruptions that are responsive to antiviral medications if taken early.
Human immunodeficiency virus	A transmissible retrovirus that causes AIDS in humans
Idiopathic	A disease having no known cause
Idiopathic TM	When TM occurs without an apparent underlying cause
Immunoglobulins	Antibodies
Immunomodulatory treatment	Treatment that diminishes immune responses
Incontinence	The inability to control excretory functions
Infusion	The therapeutic introduction of a fluid into a vein. In contrast to injection, infusion suggests the introduction of a larger volume of a less concentrated solution over a more protracted period
Isolated, idiopathic disease	A disease with unknown cause or spontaneous origin
IVIG	Intravenous immunoglobulin. Pooled antibodies from thousands of donors
Lesion	Any pathological or traumatic discontinuity of tissue or loss of function of a part
Leukemia virus	A progressive, malignant disease of the blood-forming organs, marked by distorted proliferation and development of leukocytes and their precursors in the blood and bone marrow
Lumber puncture	A procedure in which the doctor inserts a small needle into the spinal cavity in the lower back to withdraw some spinal fluid for testing. It is also known as a "spinal tap".

Lupus erythematosus	Chronic inflammatory disease in which inappropriate immune system reactions cause abnormalities in the blood vessels and connective tissue
Lyme borreliosis	Lyme disease is also called Lyme borreliosis. It is a disease of animals that can be transmitted to humans under natural conditions. In this case, a tick bearing the <i>Borrelia burgdorferi</i> organism literally inserts it into a host's bloodstream when it bites the host to feed on its blood
Lymphocytes	White blood cells, originally from stem cells that produce antibodies and attack harmful cells. There are two categories of lymphocytes: B cells and T cells.
Mass-occupying lesion	Mass: A lump or collection of cohering particles Lesion: Any pathological or traumatic discontinuity of tissue
Molecular mimicry	This theory postulates that an infectious agent may share a molecule, which resembles or "mimics" a molecule in the spinal cord. When the body mounts an immune response to the invading virus or bacterium, it also responds to the spinal cord molecule with which it shares structural characteristics
Monophasic illness	One- time occurrence
Motor	A muscle, nerve or centre that affects or produces movement
Motor nerve	A nerve conveying an impulse that excites muscular contraction
MRI	<p>Magnetic Resonance Imaging. A special imaging technique used to image internal structures of the body, particularly the soft tissues. An MRI image is often superior to a normal X-ray image.</p> <p>It uses the influence of a large magnet to polarise hydrogen atoms in the tissues and then monitors the summation of the spinning energies within living cells.</p> <p>Images are very clear and are particularly good for soft tissue, namely the brain and spinal cord, joints and the abdomen. These scans may be used for detecting some cancers or for following their progress.</p>

Multiple sclerosis	Multiple sclerosis (MS) is a chronic autoimmune disorder affecting movement, sensation and bodily functions. It is caused by destruction of the myelin insulation covering nerve fibres (neurons) in the central nervous system (brain and spinal cord).
Multisystemic disease	Relating to a disease or condition that affects many organ systems of the body
Mycoplasma pneumonia	A microorganism causing primary atypical pneumonia in humans
Myelin	Fatty tissue covering the axons of the nerves that allows efficient conduction of impulses and messages from the brain. Myelin is produced by oligodendrocytes in the CNS and by Schwann cells in the peripheral nervous system.
Myelitis	An inflammation or infection of the spinal cord
Myelogram	A set of X-rays taken after a lumbar puncture has been performed either in the neck or in the lower back. A contrast agent (dye) is injected into the sac that surrounds the spinal cord. The patient is then tilted up and down (to let the dye flow and outline the spinal cord) while the X-rays are taken.
Neurosarcoidosis	A granulomatous disease of unknown cause involving the central nervous system, usually with concomitant systemic involvement
Oligodendrocytes checked	One type of the cells comprising the oligodendroglia. (Oligodendroglia is the non-neural cells, forming part of the central nervous system.)
Paraneoplastic syndrome	A set of symptoms that is associated with cancer but is not directly caused by the cancer
Paraparesis	Partial paralysis of the lower limbs
Paraplegia	Complete paralysis of the lower half of the body including both legs, usually caused by damage to the spinal cord
Paresthesias	Abnormal neurological sensations which include numbness, tingling, burning, prickling
Peripheral	Of or relating to the surface or outer part of the body or organ; external

Plasma exchange	The removal of plasma from withdrawn blood, with re-transfusion of the formed elements into the donor done for removal of circulating antibodies or abnormal plasma constituents. The plasma removed is replaced by type-specific frozen plasma.
Plasmapheresis	Plasmapheresis is a blood purification procedure used to treat several autoimmune diseases. It is also known as therapeutic plasma exchange.
Poliomyelitis	An acute viral disease usually caused by a poliovirus and marked clinically by fever, sore throat, headache, vomiting and often stiffness of the neck and back; these may be the only symptoms of the minor illness. In the major illness, which may or may not be preceded by the minor illness, there is central nervous system involvement, stiff neck, pleocytosis in spinal fluid and perhaps paralysis; there may be subsequent atrophy of muscle groups, ending in contraction and permanent deformity.
Postvaccinal	Occurring after vaccination. Usually used in reference to an adverse reaction to the vaccine or occurrence of disease caused by the infectious agent contained in the vaccine because of an altered immune status in the recipient or a fault in the vaccine manufacture.
Sarcoidosis	A disease which can affect many organs within the body. It causes the development of granulomas. Granulomas are masses resembling little tumours. They are made up of clumps of cells from the immune system.
Schwann cells	Any of the large nucleated cells whose cell membrane spirally enwraps the axons of myelinated peripheral neurons supplying the myelin sheath between two nodes of Ranvier
Sensory	Pertaining to or subserving sensation
Sjögren's syndrome SS	Sjögren's syndrome (SS) is a disorder in which the mouth and eyes become extremely dry. Sjögren's syndrome is often associated with other autoimmune disorders. It is named after Henrik Sjögren, a Swedish ophthalmologist.

Solumedrol	A synthetic glucocorticoid (cortisone) derived from progesterone, used in replacement therapy, as an anti-inflammatory and immune system suppressant
Spastic gait	A gait characterised by stiffness of legs, feet and toes
Spinal arteriovenous malformation	Spinal: Pertaining to the spinal cord's functioning independently from the brain. Arteriovenous: Pertaining to or affecting an artery and a vein. Malformation: Defective or abnormal formation.
Spinal cord	That part of the central nervous system lodged in the spinal canal
Spinal shock	A reaction to a spinal cord injury in which the body's reflexes are lost, resulting in a limp paralysis below the point of injury. May last for several hours.
Stenosis	An abnormal narrowing or contraction of a canal (of the spinal cord)
Steroids	A group of drugs that includes the corticosteroids (cortisone), similar to hormones produced by the adrenal glands and used to relieve inflammation
Systemic	Pertaining to or affecting the body as a whole
Systemic lupus erythematosus	Systemic lupus erythematosus (also called lupus or SLE) is a disease where a person's immune system attacks and injures the body's own organs and tissues. Almost any system of the body can be affected by SLE.
T- cell	A principal type of white blood cell that completes maturation in the thymus and that has various roles in the immune system, including the identification of specific foreign antigens in the body and the activation and deactivation of other immune cells. Also called <i>T lymphocyte</i>
Thoracic	Pertaining to or affecting the chest
Thrombosis	Formation of a clot in the blood that either blocks, or partially blocks a blood vessel.
Transverse	Lying or being across, or in a crosswise direction

Vascular diseases	Diseases of the peripheral circulatory system
Vasculitis	Vasculitis refers to a varied group of disorders, which all share a common underlying problem of inflammation of a blood vessel or blood vessels. The inflammation may affect any size blood vessel, anywhere in the body

Annexure C

Anne's story

As some personal information can invariably be found in participant's stories, these stories have been removed from the distributed version of this thesis for ethical reasons. *Bona fide* researches with due ethical clearance are nevertheless welcome to approach the author for copies.

Annexure D

Bert's story

As some personal information can invariably be found in participant's stories, these stories have been removed from the distributed version of this thesis for ethical reasons. *Bona fide* researches with due ethical clearance are nevertheless welcome to approach the author for copies.

Annexure E

Cate's story

As some personal information can invariably be found in participant's stories, these stories have been removed from the distributed version of this thesis for ethical reasons. *Bona fide* researches with due ethical clearance are nevertheless welcome to approach the author for copies.

Annexure F

Drew's story

As some personal information can invariably be found in participant's stories, these stories have been removed from the distributed version of this thesis for ethical reasons. *Bona fide* researches with due ethical clearance are nevertheless welcome to approach the author for copies.

Annexure G

Eric's stories

As some personal information can invariably be found in participant's stories, these stories have been removed from the distributed version of this thesis for ethical reasons. *Bona fide* researches with due ethical clearance are nevertheless welcome to approach the author for copies.

Annexure H

Letter of consent

Section A

Information

Dear Participant

I am currently busy with my PhD in psychology under the supervision of Prof Dave Beyers at the University of Pretoria. Transverse myelitis is in many ways a neglected disease, especially with regard to the psychological care of these handicapped patients. From a perspective of positive psychology, the coping skills of transverse myelitis patients will be used to develop a coping model for general well-being. Models exist for the treatment of several disorders, physiological as well as psychological. It seems, however, that a coping model for transverse myelitis patients is relatively new in the health care of these patients.

My aim is therefore to develop a coping model for the well-being of patients with transverse myelitis. In order to develop such a coping model, I need to establish what qualities transverse myelitis patients have that help them cope with this disease.

This is a qualitative study. Herein I aim to understand and describe the experiences and coping strategies of the participants.

Title Toward the development of a coping model for the well-being of patients with transverse myelitis.

Benefits There are no financial gains rewarded for participating in this study.

Rights Participation is voluntary. You may withdraw from participation in the study at any time and without negative consequences.

Confidentiality All information that is obtained during the course of the study is strictly confidential. Any information that will be presented as part of the requirements of a doctoral study or that may be reported in scientific journals will not include any information, which identifies you as a participant in this study. If you wish to withdraw from the study, all relevant information provided by you, will be destroyed. You are assured that all information will be strictly confidential. You will be treated as anonymous, unless you specifically request in writing that your name should be mentioned. All your data will be destroyed should you choose to withdraw. All the data that will be generated in this study must and will be kept securely in electronic or paper form for a period of five years after the study has been completed. It will be shared that even though there are no immediate benefits

for them to participate in the project, it is hoped that this thesis will make a significant contribution to the well-being of transverse myelitis patients, both in South Africa and globally. There are no known emotional, physical, sociological or economical risks for anybody associated with this study.

Request

Please write your personal transverse myelitis ~~st~~ory~~o~~r experience to me in your home language, via an email. You may of course, take your time and write it when you feel ready to do so. Feel free to include any details that you want to. Your TM ~~st~~ory~~o~~r experience may be as long as you want it to be.

Researcher

Should you require more information, contact me.

My contact details are:

Name: Mart Uys

Cell: 0834525190

Email: martuys@iburst.co.za

Section B

Consent

On this day, Tuesday 19 August 2009, I _____ (name and surname) hereby give my consent that information given by me in the form of my transverse myelitis narrative may be used in the final results of the study as well as published if required.

Participant

Supervisor

_____ .

Researcher

Head of the Department of
Psychology

_____ ..

Annexure I

Ethics form

Dear Participant,

You are invited to take part in a research project that will be necessary for the completion of my PhD Psychology thesis. This study is being conducted by me, Martha-Marié Uys and it is sponsored by me. To help you to decide whether you want to participate in this study or not, it is important for you to understand what the research is about and how it will involve you. Please take the time to read the following information carefully.

Patients with transverse myelitis have strategies that help them cope with this disease. The purpose of this study is to discover what the coping qualities are of patients with transverse myelitis; to analyse these qualities for the development of a coping model for the well-being of patients with transverse myelitis and to develop, based on the analysis, a coping model for the well-being of patients with transverse myelitis. The collection of data for this study will run for three months in 2010.

You are invited to take part in the study because you are on the South African Transverse Myelitis Support Group list and also because you are easily contactable via telephones and emails.

I will ask you to electronically correspond with me. I will ask you to write me your personal story about your illness. Your personal story may be as long as you wish to make it.

Your confidentiality is guaranteed and your electronic correspondence will not be connected to your name in any report or publication. You may stay totally anonymous if you wish to do so.

If you decide to take part in this study, you may still withdraw at any time without any consequences or explaining in any way what your reasons for withdrawal are. Data generated by the study will be retained in accordance with the University of Pretoria's policy on Academic Integrity. All the data that will be generated in this study must and will be kept securely in electronic or paper form for a period of five years after the study has been completed.

Even though there are no immediate benefits for you to participate in the project, it is hoped that this thesis will make a significant contribution to the well-being of transverse myelitis patients both in South Africa and globally. There are no known emotional, physical, sociological or economical risks for anybody associated with this study.

If you decide to take part in this study, please reply to this e-mail and indicate that you wish to take part. I will then e-mail you a formal consent form that needs to be completed and signed by you. The completed and signed consent form must then be e-mailed back to me.

The results of the research will be used in my thesis for a PhD degree in psychology. The results will be analysed and published in my thesis and you may request a copy of the published research. The title of my study is *Toward the development of a coping model for the well-being of patients with transverse myelitis*.

The research proposal has been approved by the University Ethics Committee, University of Pretoria. If you are concerned about the study or how the collection of data is being conducted, you should contact the Chair of the University Research Ethics Committee at telephone: 012 420 2653 or email: patrick.chiroro@up.ac.za or patrick.chiroro@gmail.com.

If you need any further information about the study, or have additional questions or concerns, please do not hesitate to contact me at martuys@iburst.co.za or 0834525190 or 012 361-7671.

Thank you for your time to read the ethical consent document.

Kind regards
Martha-Marié Uys

Annexure J

Request for permission to use list

397 Central Park Avenue

Lynnwood

0081

10 September 2008

Dear Miss Jenny Moss

I hereby request permission to have access to the contact details of the TM patients in South Africa listed in your data basis. I am currently busy with my PhD in psychology under the supervision of Prof Dave Beyers at the University of Pretoria. I will contact the transverse myelitis patients via email and explain to them what my study is about and how they can participate.

Transverse myelitis is, as you know, in many ways a neglected disease, especially with regard to the psychological care of these handicapped patients. From a perspective of positive psychology, the coping skills of transverse myelitis patients will be used to develop a coping model for general well-being. My aim is therefore to develop a coping model for the well-being of patients with transverse myelitis. In order to develop such a coping model, I need to establish what qualities transverse myelitis patients have that help them cope with this disease.

I aim to understand and describe the experiences and coping strategies of the participants.

Title

Towards the development of a coping model for the well-being of patients with transverse myelitis.

Benefits

There are no financial gains rewarded for participating in this study.

Ethical issues

Participation is voluntary.

Participants may withdraw from participation in the study at any time and without any negative consequences.

Participants will be treated as anonymous, unless they specifically request in writing that their names should be mentioned.

Participants will not in any way be harmed.

Results will remain confidential.

Participants are assured that all information will be strictly confidential.

Participants data will be destroyed should they choose to withdraw.

Researcher

Name: Martha-Marié Uys

Student number: 81346507

Cell: 0834525190

Email address: martuys@iburst.co.za

Regards,

Martha-Marié Uys

Annexure K

Clustered themes from Anne's story

As some personal information can invariably be found in participant's stories and the clustered themes from these stories, these pages have been removed from the distributed version of this thesis for ethical reasons. *Bona fide* researches with due ethical clearance are nevertheless welcome to approach the author for copies.

Annexure L

Clustered themes from Bert's story

As some personal information can invariably be found in participant's stories and the clustered themes from these stories, these pages have been removed from the distributed version of this thesis for ethical reasons. *Bona fide* researches with due ethical clearance are nevertheless welcome to approach the author for copies.

Annexure M

Clustered themes from Cate's story

As some personal information can invariably be found in participant's stories and the clustered themes from these stories, these pages have been removed from the distributed version of this thesis for ethical reasons. *Bona fide* researches with due ethical clearance are nevertheless welcome to approach the author for copies.

Annexure N

Clustered themes from Drew's story

As some personal information can invariably be found in participant's stories and the clustered themes from these stories, these pages have been removed from the distributed version of this thesis for ethical reasons. *Bona fide* researches with due ethical clearance are nevertheless welcome to approach the author for copies.

Annexure O

Clustered themes from Eric's Stories

As some personal information can invariably be found in participant's stories and the clustered themes from these stories, these pages have been removed from the distributed version of this thesis for ethical reasons. *Bona fide* researches with due ethical clearance are nevertheless welcome to approach the author for copies.