Coping strategies and quality of life in patients with multiple sclerosis (MS): A South African online perspective

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DECLARATION

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Abstract

The primary aim of this study was to explore the relationship between coping strategies used by individuals with multiple sclerosis (MS) and their quality of life (QoL) in the context of South Africa. Two hundred individuals (18 years and older) diagnosed with MS were recruited from the online Facebook support group, Multiple Sclerosis South Africa Western Cape. Participants were asked to complete a survey that consisted of a biographical questionnaire, a coping questionnaire (Brief Cope) as well as a QoL questionnaire (Multiple Sclerosis International Quality of Life questionnaire [MusiQoL]). Correlation analyses were performed to explore the relationship between QoL and coping. Independent sample t-tests and one-way ANOVA's were utilised to ascertain if there were differences in the mean coping and QoL scores between different groups (male and female) and sub-types of MS namely relapsing/remitting (RRMS), primary progressive (PPMS), secondary progressive (SPMS) and progressive relapsing (PRMS). A multiple regression was conducted to explore the predictors of QoL (independent variables: age, education, level of income, MS subtype, coping style, and dependent variable: QoL). The results of this study indicated that a relationship exists between the coping strategies used by individuals with MS and their level of QoL. Specifically, a significant positive relationship was identified between the use of emotional support, venting, positive reframing, acceptance and QoL. In contrast, a significant negative relationship was identified between the use of behavioural disengagement, mental disengagement, substance use, self-blame, and QoL. The results also highlighted a low QoL among this sample of South Africans with MS (measured with a mean global index score of 51.33 on the MusiQoL). Moreover, it was ascertained that MS sub-type had an affect on the coping strategies and QoL of individuals with MS in this sample. Finally, the results of this study also showed that planning (1.14 %), positive reframing (1.69%), acceptance (1.29 %), behavioural disengagement (1.23 %), and self-blame (9.85 %) account for some of the variance in the QoL of this sample. The findings of this study provided greater insight into the patterns of coping and QoL of individuals with MS in South Africa. These findings also highlight that the type of coping strategies used by the MS participants in our sample had a significant negative influence on their level of QoL.

Key words: Multiple sclerosis (MS), Coping, Quality of Life (QoL), South Africa.

Opsomming

Die primêre doel van hierdie studie was om die verhouding tussen die hantering strategieë gebruik deur individue met MS en hul lewensgehalte te ondersoek in die konteks van Suid-Afrika. 200 Individue (18 jaar en ouer) wat met MS gediagnoseer is, is gewerf vanaf die aanlyn Facebook-ondersteuningsgroep, "Multiple Sclerosis South Africa Western Cape". Deelnemers is gevra om 'n opname te voltooi wat bestaan het uit 'n biografiese vraelys, 'n hantering strategieë vraelys ("Brief Cope") asook 'n lewensgehalte vraelys ("Multiple Sclerosis International Quality of Life vraelys [MusiQoL]"). Onafhanklike steekproef-toetse en eenrigting ANOVA's is aangewend om vas te stel of daar verskille was in die gemiddelde hantering strategieë en lewensgehalte tellings tussen verskillende groepe (manlik en vroulik) en sub-tipes van MS naamlik, herhalende / oormaking MS, primêre progressiewe MS, sekondêre progressiewe MS en progressiewe terugval MS. Korrelasie-ontledings is uitgevoer om die verband tussen lewensgehalte en hantering strategieë te ondersoek. 'n Veelvuldige regressie is uitgevoer om die voorspellers van lewensgehalte te ondersoek. Die resultate van hierdie studie het aangedui dat daar 'n verband bestaan tussen die hanteringstrategieë wat gebruik word deur individue met MS en hul lewensgehalte vlak. Meer spesifiek, 'n betekenisvolle positiewe verband is geïdentifiseer tussen die gebruik van emosionele ondersteuning, ontlugting, positiewe herraming, aanvaarding en lewensgehalte. In kontras hiermee is 'n betekenisvolle negatiewe verband geïdentifiseer tussen die gebruik van gedrags-ontkoppeling, geestelike onbetrokkenheid, dwelmgebruik, selfverwyt en lewensgehalte. Die resultate het ook beklemtoon dat 'n lae lewensgehalte (gemeet deur 'n gemiddelde globale indekspunt van 51,33) onder hierdie steekproef van Suid-Afrikaners met MS gevind is. Verder is vasgestel dat MS-subtipe 'n invloed het op die hanteringsafwyking en QoL van individue met MS in hierdie steekproef. Laastens, het hierdie resultate getoon dat beplanning (1,14%), positiewe herraming (1,69%), aanvaarding (1,29%), gedrags-ontkoppeling (1,23%) en selfverwyt (9,85%) verantwoordelik was vir ‘n deel van die afwyking in die lewensgehalte van hierdie deelnemers. Hierdie bevindings van hierdie studie het groter insig gebied in die hanterings patrone en lewensgehalte van individue met MS in Suid-Afrika. Hierdie bevindings beklemtoon ook dat die tipe hantering strategieë wat deur die MS-deelnemers in hierdie studie gebruik was 'n beduidende negatiewe invloed op hul vlak van lewensgehalte gehad het.

Sleutelwoorde: Veelvoudige sklerose, Hantering strategieë, Lewensgehalte, Suid-Afrika.

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Abbreviations

CIS	Clinically Isolated Syndrome
CNS	Central Nervous System
CSF	Cerebrospinal Fluid
DIS	Dissemination in space
DIT	Dissemination in time
DMT(s)	Disease-Modifying Treatment(s)
EBV	Epstein–Barr virus
HLA	Human Leukocyte Antigen
HREC	Health Research Ethics Committee
LMIC	Low and Middle-Income Country
MS	Multiple Sclerosis
MusiQoL	Multiple Sclerosis International Quality of Life questionnaire
IM	Infectious Mononucleosis
PPMS	Primary Progressive Multiple Sclerosis
PRMS	Progressive Relapsing Multiple Sclerosis
QoL	Quality of Life
RRMS	Relapsing/Remitting Multiple Sclerosis
SPMS	Secondary Progressive Multiple Sclerosis
TTSC	Transactional Theory of Stress and Coping

VIF	Variance Inflation Factor

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Chapter 1

Introduction

1.1. Introduction and rationale for the study

Multiple sclerosis (MS) is described as a chronic neurological illness that is demonstrated by the demyelisation of the central nervous system (CNS) resulting in inflammation as well as axonal and neuronal deterioration (Fernández et al., 2010). Furthermore, MS can be sub-categorised into four types, namely relapsing/remitting (RRMS), primary progressive (PPMS), secondary progressive (SPMS) and progressive relapsing (PRMS) (McCabe, 2005). In 2013, there were an estimated 2.3 million cases of MS and an estimated prevalence of 30 out of 100 000 individuals worldwide (Dua & Rompani, 2008). The number of individuals diagnosed with MS highlights the fact that MS is a relevant health concern (Dua & Rompani, 2008). Individuals diagnosed with MS are a heterogeneous group since damage to different parts of the CNS results in diverse symptoms, and therefore individuals will have different experiences during their disease journey (Malcomson, Lowe-Strong, & Dunwoody, 2008). A list of physical symptoms has been compiled by Reipert (2004) and includes sensory disorders, limb weakness, walking ataxia, fatigue, pain, and sexual dysfunction. In addition to the physical symptoms, cognitive dysfunctions, major depression, and anxiety are psychological symptoms often reported by individuals with MS (Feinstein & Freeman, 2015).

Individuals with MS are recurrently faced with unpredictable periods of deteriorating health, because of the uncertain nature of MS and the fact that different parts of the body are influenced by the illness. These prolonged periods of ill health often compel individuals with MS to rely on certain coping strategies (including problem-solving, seeking social support, avoidance and denial) to manage the unpredictability and health deterioration caused by MS (McCabe, McKern, & McDonald, 2004). Using the work of Lazarus and Folkman (1984) coping is defined as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 110).

With regards to coping, studies have shown that individuals with MS employ certain coping strategies less often than the general population. For example, in a study by McCabe and McKern (2002) the authors demonstrated that, compared to a sample from the general population, individuals with MS used coping strategies such as task-orientation and a positive attitude less often, whereas the general population used such coping strategies more often. Similarly, in another study by Goretti et al. (2009) seeking social support and a positive attitude were listed as coping strategies least used by individuals with MS. Goretti et al. (2010) also reported that the MS population use detachment and coping strategies intended to avoid the problem (such as denial, mental and behavioural disengagement) more regularly.

A systematic review by Kar et al. (2017) identified several factors that disrupt the way in which individuals with MS cope with their illness. These are categorized into individual characteristics (gender, level of education, and employment status), clinical features (disability due to MS, clinical course, and disease duration), and psychological factors (mood status, self-esteem, and attitude). Moreover, these factors are claimed to impair the process of adapting to MS, worsen the daily functioning of individuals and ultimately negatively affect their quality of life (QoL), which has been reported in several studies (Mitchell, Benito-León, González, & Rivera-Navarro, 2005; Kar et al., 2017 Motl, McAuley, Wynn, Sandroff, & Suh, 2013; Price & Harding, 1993).

With regards to QoL, research indicates that in comparison to the general population QoL is lower amongst those with MS (Janardhan & Bakshi, 2002; Kes et al., 2013; McCabe & McKern, 2002). Taking into consideration the unpredictability of the disease, it is not surprising that MS has a significant negative influence on the QoL of those diagnosed (McCabe & McKern, 2002). Since individuals with MS have no control over their symptoms or when they will worsen, research has indicated that these individuals use variety of coping behaviours to manage this (Plow et al., 2009; Sanaeinasab et al., 2017). It has been established that there is a connection between the type of coping and QoL (McCabe et al., 2004; Montel & Bungener, 2007; Lode et al., 2007) Certain coping behaviours such as task-orientation and a positive attitude relate to an enhanced QoL, as seen by higher scores on QoL measurements such as the questionnaire used in numerous studies (McCabe et al., 2004; Montel & Bungener, 2007; Lode et al., 2007; Plow et al., 2009; Sanaeinasab et al., 2017). For instance, in a study by Lode et al. (2007) the authors demonstrated that the use of coping strategies such as seeking social support for instrumental reasons and planning (that were intended to solve the problem) were related to a higher score on the QoL measure, indicating an enhanced QoL. In contrast, research has established that the practice of strategies such as avoidance, wishful thinking, and self-accusation have been associated with lower QoL levels (Farran et al., 2016). The detection of coping strategies that are positively associated with QoL (such as social support, planning and a positive attitude) could decrease the disease burden experienced by individuals with MS. By detecting and incorporating coping strategies associated with high QoL, individuals with MS are able to manage their emotions and illness more sufficiently. Furthermore, this information is also important for adjusting future therapeutic interventions that are aimed at introducing the use of positive coping strategies (such as seeking social support, planning, and a positive attitude) that could improve the QoL of those with MS (McCabe et al., 2004; Montel & Bungener, 2007; Plow et al., 2009; Sanaeinasab et al., 2017).

In recent years, significant advances have been made in research on MS, such as the introduction of oral therapies and the detection of formerly unidentified genetic risk variants (McKay & Tremlett, 2015). The international scope of MS related research has also been broadening, with research emerging from countries such as India, Iran, and Canada (Bhatia, Bali, & Chaudhari, 2015; Metz et al., 2017; Sahebi, Amiri, & Jami, 2017). Furthermore, evidence suggest that a link exists between the coping strategies used and an individuals' QoL (Farran et al., 2016; Goretti et al., 2009; Goretti et al., 2010; McCabe et al., 2004; Mitchell et al., 2005). Findings from research suggest that strategies such as a task-orientation, positive attitude, and planning are related to a better QoL, whereas coping strategies such as avoidance, wishful thinking, and self-accusation are associated with a worse QoL (Gemmell et al., 2016; Hesselink et al., 2004; Yetwin, Mahrer, John, & Gold, 2018). However, there is no such evidence available in the context of South Africa. Based on a South African MS study by Modi et al. (2008) it was determined that South Africa is regarded as a medium incidence (5 - 30 per 100 000) region, making MS a relevant health concern. There is however still a scarcity in research, especially that of a psychosocial nature, on MS in the context of South Africa (Modi et al., 2008). It is of vital importance to investigate patterns of coping and QoL in a developing country such as South Africa, as it is possible that South Africans with MS face unique barriers and stressors related to contextual, social, political and economic influences. This dearth of research indicates the need for South African research regarding coping and QoL amongst individuals with MS. The primary aim of this study was therefore to investigate the relationship between the coping strategies used by individuals with MS and their QoL in South Africa.

1.2. Definition of key terms

1.2.1. Multiple sclerosis

MS is defined as a chronic ongoing degenerative neurological illness that is illustrated by the demyelisation of the central nervous system. The demyelisation of the central nervous system causes inflammation as well as axonal and neuronal deterioration, which leads to the symptoms related to MS (Fernández et al., 2010; Pretorius & Joubert, 2014). These symptoms consist of sensory disorders, one-sided optic neuritis clumsiness, Lhermitte's sign[1], limb weakness, walking ataxia, fatigue, pain, and bowel, bladder, sexual dysfunction (Reipert, 2004).

1.2.2. Coping

Coping is defined as cognitive and behavioural endeavours that are continually changing and aimed at managing particular external and/or internal stressors. These stressors are then evaluated by an individual as demanding or being beyond their resources (Lazarus and Folkman, 1984). Two other definitions of coping are provided by Dewe (1987) and Latack (1986) respectively. In his research Dewe (1987) defines coping as attempts (of an active and/or passive nature) made in a response to a threatening situation with the goal of reducing the discomfort experienced. Moreover, Latack (1986) defines coping as a reaction to situations which are characterised by an individual as uncertain with important consequences. For the purpose of this study, coping is defined by drawing on the research of Lazarus and Folkman (1984).

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[1] *Lhermitte's sign* is defined as a shock-like feeling that occurs when the neck is flexed (Reipert, 2004).

1.2.3. Problem-focused coping strategies

Problem-focused coping strategies are defined as efforts aimed at resolving stressful situations such as eliminating the source of stress, searching for information to handle the situation, and detaching oneself from the situation (Lazarus & Folkman, 1984; Lazarus, 1999).

1.2.4. Emotion-focused coping strategies

Emotion-focused coping strategies denote efforts aimed at emotional regulation, i.e. when an individual decreases emotion produced by the stressful situation while not focussing on the specific problem (Lazarus & Folkman, 1984; Lazarus, 1999). These strategies include efforts such as isolation, avoidance, blame, minimalizing emotions, wishful thinking (hoping that your problem will go away) looking for social support, and meditation (Ahadi et al., 2014; Rice, 2000).

1.2.5. Avoidance coping strategies

Avoidance coping strategies are defined as unintended efforts directed at adjusting to a stressor through avoidance of the stressor or diminishing feelings associated with the stressor (Eschenbeck, Kohlmann, & Lohaus, 2007). Avoidance coping strategies consist of efforts such as behavioural disengagement (reducing efforts to deal actively with a stressor) mental disengagement (turning to other activities to distract from a stressor), denial, substance use, and self-blame (Lazarus & Folkman, 1984; Lazarus, 1999).

1.2.6. Quality of life

Quality of life (QoL) is an individuals' outlook on their level of satisfaction concerning numerous aspects of well-being, which includes emotional, social, cultural and economic aspects (Benito-León, Manuel-Morales, Rivera-Navarro, & Mitchell, 2003; Price & Harding, 1993). The World Health Organization Quality of Life (WHOQOL) Group(1994) defines QoL as

> Individual's perceptions of their position in life in the context of the culture and value system where they live, and in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way a person's physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to salient features of the environment (p. 1405).

1.3. Aims and objectives of the research

The primary aim of this study was to determine whether a relationship exists between the coping strategies used by people with MS and their QoL in the context of South Africa. The objectives of this study was to (1) investigate the relationship between coping strategies used by individuals with MS and their QoL, (2) to determine whether gender and MS sub-type have an influence on the types of coping strategies individuals with MS use, (3) to determine if gender and MS sub-type have an influence on their QoL, and lastly (4) to identify the predictors of QoL in this sample of participants.

1.4. Research questions

With the research aim in mind, this study seeks to answer the following research questions:

1. Is there a relationship between the coping strategies used by individuals with MS and their QoL?
2. Do males and females differ in terms of coping strategies used, and is this difference significant?
3. Do MS sub-types differ in terms of coping strategies used, and is this difference significant?
4. Do males and females differ in terms of overall QoL score, and is this difference significant?

5. Do MS sub-types differ in terms of overall QoL score, and is this difference significant?
6. Do biographical factors (such as gender, age, employment, relationship status), clinical factors (MS sub-type), and coping strategies (Brief cope sub-scales) have an influence on the QoL of individuals with MS?

1.5. Overview of chapters

Chapter 1 provided a brief overview of what this study is about. The rationale, aim, and objectives of this study was also discussed.

Chapter 2 provides an overview of prominent research findings (international and local where possible) regarding MS and the topics of aetiology, epidemiology, incidence and prevalence, classification, diagnosis, symptomology, treatment, coping strategies and QoL of those diagnosed with MS.

Chapter 3 elaborates on Lazarus and Folkman's (1984; 1987) transactional theory of stress and coping (TTSC) as a framework for explaining the coping strategies used by individuals with MS. The major components and key concepts are defined and described, as well as the applicability use of this theory in the context of this specific study.

Chapter 4 provides in-depth detail about the research methodology employed in this study. Discussion points include the research aims, question and hypothesis, research design, participants and recruitment procedure, data collection (materials and procedures), as well as data analysis of this study. This chapter ends with the ethical considerations of the current study.

Chapter 5 presents the results and key findings of the study. The chapter starts with the biographical results of the study as well as the comparative statistics for each of the used measures. Next, the reliability analyses for the measures (Brief Cope and MusiQoL) are reported. This is followed by the relationship between QoL and coping. Thereafter, I report on the findings of the results of the independent sample t-tests and ANOVA’s. This chapter ends with the results of the multiple regression analysis, used to explore the predictors of QoL in this sample.

Chapter 6 covers a discussion of the key findings of the current study. This is done through the integration of literature as well as Lazarus and Folkman’s (1984) transactional theory on emotion and coping in the findings.

Chapter 7 comprises of the limitations and the significance of the current study are presented. Next, some recommendations for future research is presented. The chapter closes with concluding remarks on the study.

Chapter 2

Literature review

2.1. Introduction

In this chapter, I provide an overview of prominent research findings (international and local where possible) regarding MS and the topics of aetiology, epidemiology, incidence and prevalence, classification, diagnosis, symptomology, treatment, coping strategies and QoL of those diagnosed with MS.

2.2. Defining multiple sclerosis

MS is a permanent debilitating-related neurological illness that involves the demyelisation of the CNS, which results in inflammation, axonal and neuronal deterioration, as well as lesions in the white and grey matter of the CNS (Fernández et al., 2010; Pretorius & Joubert, 2014; Tsang & Macdonell, 2011). During the process of demyelisation (where the myelin is damaged or destroyed completely), the distribution of nerve impulses is reduced and, at times, even stopped. It is possible for the myelin sheath around the axon to be repaired through a process called remyelisation and is generated through the production of oligodendrocytes. This remyelisation is however not a frequent occurrence in the case of MS. If there are not enough oligodendrocytes near the lesion, remyelisation will not occur or will only partly occur. If this is the case and remyelisation does not occur, the affected nerve will continue to function in an irregular manner. Apart from remyelisation, the damaged myelin can also be replaced by scar tissue. However, once axons are sacrificed, they never fully regain previous functioning (Reipert, 2004).

Research indicates that roughly 85% of people diagnosed with MS begin with an incident of neurological disorder that typically evolves over days or weeks and is referred to as a clinically isolated syndrome (CIS). CIS is the first demyelinating event, and these individuals tend to have several dormant lesions on their brain or spinal cord MRI (Tsang & Macdonell, 2011). Research has shown that, by beginning with a treatment of β-interferon after the first CIS, a definite development of MS can be delayed (Cross et al., 2012).

2.3. Classification of MS

MS can be sub-categorised into four types, namely RRMS, PPMS, SPMS and PRMS (McCabe 2005; Sand, 2015). Research shows that the average age of onset for PPMS and SPMS is 40 years, in comparison to RRMS and SPMS, which is 30 years of age (Courtney et al., 2009; McKay, Kwan, Duggan, & Tremlett, 2015).

The first type, RRMS, is the most common type of MS and is found in an estimated 80% of individuals diagnosed with MS (Courtney et al., 2009). RRMS is characterised through a sequence of relapses, followed by partial or complete disappearance of symptoms until another relapse occurs (Reipert, 2004; Sand, 2015). The second sub-type, PPMS, involves a process whereby individuals are likely to encounter a steady progression of symptoms and decline in physical competences. PPMS is approximated to be prevalent in 10 % to 20 % of individuals with MS (Courtney et al., 2009; Reipert, 2004; Sand, 2015). SPMS, which is the third sub-type, develops within 10 years in about 50% of individuals who are initially diagnosed with RRMS. SPMS is distinguished by a continuous development of clinical neurological damage with or without relapses and remissions. SPMS is often related to lesser formation of inflammatory lesions in comparison to RRMS, however the burden of the illness still progresses which is thought to be caused by increased levels of axonal loss (Reipert, 2004). The last and rarest sub-type is PRMS, which is characterised by a steady rate of dysfunction progress, followed by phases where symptoms often worsen to the point of hospitalisation (Courtney et al., 2009; Sand, 2015).

2.4. Aetiology

Although the exact causes of MS are still unknown, research by several authors suggests that MS is implicated by a multifaceted interaction of various genetic and environmental factors (Baranzini & Oksenberg, 2017; Cross et al., 2012; Küçükali, Kürtüncü, Çoban, Çebi, & Tüzün, 2015; Tsang, 2011; Reipert, 2004; Pantazou, Schluep, & Du Pasquier, 2015; Young, 2011).

2.4.1. Genetic factors

The genetics implicated in the development of MS is demonstrated by various familial, monozygotic and dizygotic twin studies (Baranzini & Oksenberg, 2017). Epidemiological studies have indicated that approximately 1.9 - 4.7 % of individuals with MS have a family member diagnosed with MS. Twin studies have revealed that monozygotic twins have a higher concordance rate (20 – 30 %) in comparison to dizygotic twins (2 – 5 %), which provides a strong argument for the genetic aetiology in MS development. Additionally, studies have established that the main gene that leads to MS susceptibility is in the human leukocyte antigen (HLA) locus, and particular HLA patterns such as DRB1*1501 allele. The HLA locus comprises of numerous genes that serve crucial purposes in the immune system (Cross et al., 2011; Pantazou et al., 2015). A study by Westerlind et al. (2014) supports this finding and suggests that the HLA-DRB1*1501 allele explains roughly 50 % of the genetic risk and makes an individual three times more likely to develop MS.

2.4.2. Environmental factors

The risk factors most commonly associated with MS include exposure to the Epstein–Barr virus (EBV), low serum vitamin D levels, and cigarette smoking (Pantazou et al., 2015). Each of these factors have a specific relation to how it increases risk for developing MS, however exposure to the EBV and a lack of vitamin D are currently regarded as the most prominent environmental risk factors (Pantazou et al., 2015).

2.4.2.1. Epstein–Barr virus (EBV)

EBV is a global human herpes virus that holds the distinctive capability to "infect, activate, and latently persist in B-lymphocytes for the lifetime of the infected individual" (Abdelrahman, Selim, Hashish, & Sultan, 2014, p. 92). Primary EBV infection often ensues asymptomatically during early childhood. It is however possible that, if EBV is contracted in adolescence or adulthood, to cause a severe feverish illness- known as infectious mononucleosis (IM). A study by Küçükali et al. (2015) found that individuals exposed to the EBV are twice as likely to develop MS when compared to healthy individuals. This risk further increases (to two or three times higher) if EBV is contracted during adolescence (as opposed to during infancy) and develops into IM (Correale & Gaitan, 2015).

2.4.2.2. Vitamin D levels

Epidemiological studies have indicated that the prevalence of MS is influenced by latitude, therefore addressing the possible effect of sun exposure (vitamin D) on MS. Low vitamin D levels are often found in MS patients, which could be caused by inadequate sunlight exposure or decreased consumption of vitamin D through diet (Orton et al., 2011). An epidemiological study by Orton et al. (2011) explored the relationship between sun exposure and MS among a French population and found that the prevalence of MS was higher in areas with less ultra-violet radiation (UVR) exposure (i.e. areas of higher latitude). Additionally, a study by Ascherio et al. (2014) ascertained that low quantities of vitamin D in MS patients are related to a higher prevalence of relapse and more rapid disease progression.

2.4.2.3. Cigarette smoking

Cigarette smoking is not only a risk factor for MS, but for other associated auto-immune diseases such as rheumatoid arthritis and systemic lupus erythematosus (Pantazou et al., 2015). Hedstrom, Baarnhielm, Olsson, and Alfredsson (2011) argue that it is not only the act of smoking that increases the risk of developing MS, but that lung irritation caused by exposure to tobacco smoke also has an influence. In relation to cigarette smoke exposure, a population-based case control French study found that MS prevalence rates are higher in children whose parents smoke at home. Individuals who smoke are twice as likely to develop MS. It has also been found that smokers with MS often experience a faster disease deterioration (Pantazou et al., 2015).

2.5. Epidemiology of MS

MS is regarded as one of the world's most widespread neurologic disorders, with it being the primary reason of neurologic disability amid young adults (Browne et al., 2014). Despite MS being one of the most widespread neurologic disorders, information regarding the global epidemiological information on MS is sparsely available and out of date, especially in the South African context (Browne et al., 2014).

2.5.1. Incidence and prevalence of MS

Although the prevalence of MS tends to fluctuate significantly throughout the world, in 2013 there were an estimated 2.3 million cases of MS and an estimated prevalence of 30 per 100 000 individuals worldwide (Dua & Rompani, 2008). Additionally, high rates of MS are often reported in North America and Europe (100 per 100,000 individuals), with lower rates in Eastern

Asia and sub-Saharan Africa with a prevalence of 2 per 100,000 individuals (Leray, Moreau, Fromont, & Edan, 2016). In 2008 the global average approximated incidence of MS was 2.5 per 100 000. When analysed regionally, the average approximated incidence of MS in 2008 was as follows: Europe (3.8 per 100 000), the Eastern Mediterranean (2 per 100 000), the Americas (1.5 per 100 000), the Western Pacific (0.9 per 100 000) and Africa with 0.1 per 100 000 (Dua & Rompani 2008).

Moreover, a study by Modi et al. (2008) determined that South Africa is considered a medium incidence (5 - 30 per 100 000) region. The fact that South Africa is considered a medium incidence region makes MS a significant well-being concern. This study was the only South African study on the incidence of MS found in the literature, and prevalence of MS in this country has not yet been entirely accurately established.

2.5.2. Age and gender

The age of onset for MS is typically between 20-40 years of age (Cross et al., 2011; Sand, 2015). The onset of MS is also earlier in women (between 20-40 years of age) in comparison to men who usually develop MS between the ages of 30 and 40 years (Cross et al., 2011). With regards to gender differences, research suggests that an estimated 70 % of all individuals diagnosed with MS are women, with a female-to-male ratio of about 2:1 (Cross et al., 2011). A study by Reipert (2004) suggests that this gender ratio could be due to the protective effect of male testosterone levels as the development of MS in males corresponds with the beginning of a drop-in testosterone levels.

2.6. Diagnosis of MS

The diagnosis of MS can often be an extensive and challenging process as there are no laboratory tests that lead to a definite diagnosis of MS (Pretorius & Joubert, 2014; Sand, 2015).

Diagnostic criteria were however developed by McDonald et al. (2001) and revised in 2005, 2010 and again in 2017 resulting in the recent 2017 Revised McDonald Criteria (Thompson et al., 2017). A diagnosis of MS is therefore based on a clinical diagnosis that is reinforced by magnetic resonance imaging (MRI) and laboratory findings of cerebrospinal fluid (CSF). These criteria stress the importance of determining dissemination of lesions in space (DIS) and time (DIT) as well as eliminating alternate diagnoses (Polman et al., 2011; Pretorius & Joubert, 2014). DIS is defined as the "growth of lesions in distinct anatomical locations within the CNS-i.e., indicating a multifocal CNS process", while DIT is described as "the growth or presence of new CNS lesions over time" (Thompson et al., 2017; p. 163).

The use of the McDonald Criteria, supplemented by the advancements in MRI and CSF testing, have ensured that MS can be diagnosed with more specificity and sensitivity, permitting improved counselling of patients and earlier treatment plans. Additionally, it remains imperative that the McDonald criteria must be mainly applied in patients presenting with an archetypal CIS (Polman et al., 2011; Thompson et al., 2017).

The 2017 revision of the McDonald criteria (displayed in Table 2.1) was executed to allow for an earlier, more sensitive, and more precise diagnosis subsequently allowing diagnostic certainty and early therapeutic intervention to be ascertained at the earliest time (Thompson et al., 2017). The following alterations were made to the 2010 McDonald Criteria: the occurrence of CSF-specific oligoclonal bands permits a diagnosis of MS in patients presenting with a archetypal CIS and clinical or MRI determination of DIS; in the case of patients who present with supratentorial, infratentorial, or spinal cord syndrome, one can make use of symptomatic lesions to determine DIS or DIT; DIS can be established by cortical lesions; and lastly a temporary disease course (RRMS, PPMS, or SPMS) must be identified as well as identifying if the course is active/not, and progressive/not (Thompson et al., 2017).

Table 2.1

2017 Revised McDonald Criteria (Thompson et al., 2017).

Clinical presentation (attacks)	Lesions	Additional data for diagnosis
≥ 2 attacks	≥ 2 lesions	None
≥ 2 attacks	1 (as well as clear-cut historical evidence of a previous attack involving a lesion in a distinct anatomical location)	None
≥ 2 attacks	1 lesion	DIS demonstrated by an additional clinical attack implicating a different CNS site or by MRI
1 attack	≥2 lesions	DIT demonstrated by an additional clinical attack or by MRI OR demonstration of CSF-specific oligoclonal bands
1 attack	1 lesion	DIS demonstrated by an additional clinical attack implicating a different CNS site or by MRI and DIT demonstrated by an additional clinical attack or by MRI OR demonstration of CSF-specific oligoclonal bands

Note. DIS = dissemination of lesions in space, DIT = dissemination of lesions in time, CNS = central nervous system, MRI = magnetic resonance imaging, CSF = cerebrospinal fluid.

2.7. MS in the context of South Africa

Upon reviewing the literature on MS in the South African context, only two recent studies were found. The first study is by Modi et al. (2008), who devised a questionnaire to determine qualitative data from 430 South Africans diagnosed with MS. Their study ascertained that respondents were mainly female (73 %), between the ages of 30 – 59 (71 %), and white (89 %). Relating to MS sub-types, this study found that the predominant type of MS in their sample was RRMS (46 %), followed by 17% of the sample not being sure of their type of MS, 12 % categorised as having benign MS, and 12% diagnosed with PPMS (Modi et al., 2008).

The second study is a qualitative study by Pretorius and Joubert (2014) of which the aim was to examine the personal encounters and challenges of a group South African individuals with MS. Similar to what is found in international research, the participants in this study consisted of mostly women (70 %), with the ages ranging between 38 and 71 years. Relating to MS subtypes, the majority of this sample were diagnosed with SPMS (50 %), followed by RRMS (40 %), and lastly one participant (10 %) was diagnosed with PPMS (Pretorius & Joubert, 2014). These figures are similar to what is reported in international research regarding the gender ratio, age of onset and subtypes of MS (Leray et al., 2016; Reipert, 2004; Thompson et al., 2017).

2.8. Symptoms of MS

Symptoms of MS and the severity thereof vary immensely, since it can exist in different parts of the body and therefore differs from individual to individual (Reipert, 2004). It has however been found that although MS has a heterogeneous disease course, most individuals with MS start with a relapsing-remitting course, which in time evolves into steady disability progression (Cross et al., 2011). The symptoms most often experienced by individuals diagnosed with MS can be divided into physical symptoms and psychological symptoms. The type of MS influences the severity of both physical and psychological symptoms. Therefore, indicating that the severity of symptoms experienced by individuals with progressive MS is more intense (Chiaravalloti & DeLuca, 2008).

2.8.1. Physical symptoms

Reipert (2004) put together a list of physical symptoms often experienced by individuals with MS. These symptoms include "sensory disorders, one-sided optic neuritis, Lhermitte's sign, clumsiness, limb weakness, walking ataxia, fatigue, pain, and bowel-, bladder-, and sexual-dysfunction" (Reipert, 2004; p.336). Of these, the symptoms that are most widely experienced by individuals with MS include mobility difficulties, fatigue and pain (Feinstein & Freeman, 2015).

A study by Feinstein and Freeman (2015) ascertained that roughly 80% of study patients experience walking difficulties and 70% present with weakness (reduced muscle strength) within 10 to 15 years of diagnosis. Additionally, 90% of patients reported that fatigue is one of their most troubling symptoms, and an important determinant of QoL. This same study found that the debilitating symptoms experienced by individuals with MS led to the discovery that, when compared to individuals with other chronic illnesses (such as such as asthma, chronic kidney disease, and chronic pain), MS patients can do the least amount of physical activity (i.e. at the lowest end of the physical activity scale). Concerning pain, Feinstein and Freeman (2015) reported pain-prevalence according to MS subtypes as follows: RRMS 50%, PPMS 70.3%, and SPMS 69.8%.

2.8.2. Psychological symptoms

In addition to the physical symptoms experienced by individuals with MS, a range of psychological symptoms is often present. These symptoms include cognitive dysfunctions, major depression and anxiety, which have been related to reduce devotion to therapy, increased fatigue, and lower QoL (Feinstein & Freeman, 2015; Fiest et al., 2016). Additionally, the severity of these symptoms is determined by the type of MS, with progressive MS resulting in more severe symptoms (Chiaravalloti & DeLuca, 2008; Sarısoy, Terzi, Gümüş, & Pazvantoğlu, 2013).

2.8.2.1. Cognitive dysfunctions

Research regarding cognitive dysfunction in MS patients (at earlier and later stages) report prevalence rates ranging from 43% to 70% (Chiaravalloti & DeLuca, 2008; Rocca et al., 2015; Sarısoy et al., 2013). The cognitive functions more often affected by MS includes executive functioning, attention, effectiveness of information processing, processing speed, and long-term memory. Problems with long-term memory has been found to be the most consistently experienced cognitive dysfunction amongst individuals with MS, with the prevalence ranging from 40 % to 65 % (Chiaravalloti & DeLuca, 2008). Difficulties with long-term memory has to do with difficulty in learning new information and often results in poor decision-making skills (Chiaravalloti & DeLuca, 2008; Rocca et al., 2015).

2.8.2.2. Depression

Although the exact cause of depression amongst MS patients is still unclear, possible causes include that depression could be a reaction to having a chronic debilitating illness, it could be a manifestation of the underlying damage to the CNS caused by MS. It is also possible that the individual was already depressed before receiving a MS diagnosis and that the onset of MS made the depression worse (Koch et al., 2015). In a study by Feinstein and Freeman (2015) the authors reported that between a third and half of all patients with MS will develop major depression. Similarly, Chiaravalloti and DeLuca (2008) found that approximately 60% of individuals diagnosed with MS have depression.

In the general population (those not diagnosed with MS), depression is commonly defined as an episodic disease (lasting for a certain amount of time) from which patients recover either partially or fully. However, depression in patients with MS has been found to last longer and affect several cognitive functioning aspects, which include abstract reasoning, working memory, processing speed, executive functioning as well as learning and memory functions (Chiaravalloti & DeLuca, 2008). Similar to research on other MS related symptoms, depression is affected by the type of MS, with depression scores being higher for those with progressive MS sub-types (Sarısoy et al., 2013).

2.8.2.3. Anxiety

The focus of research regarding MS and psychological ailments tend to focus on depression and often overlooks anxiety. Anxiety is however present amongst individuals with MS with the prevalence ranging from 14% to 45% (Hartoonian et al., 2015). Results of a study by Sarısoy et al. (2013) showed that individuals with MS often experience a permanent state of anxiety and excessive worry. This permanent anxious state could be attributed to the fact that MS is such an unpredictable illness where progressions and relapses can occur without warning. A list of factors that could result in higher levels of anxiety include being female, high levels of fatigue, MS exacerbations, depression, having RRMS, as well as increased disability due to MS (Hartoonian et al., 2015).

2.9. Treatment for MS

Currently, there is no cure for MS. There are however drugs available to slow down the progression of the disease and the frequency of attacks (referred to as disease-modifiers) as well as medication to treat some of the symptoms (Wingerchuk, & Carter, 2014). The symptoms that are treatable through medication include spasticity, fatigue, intention tremor, urinary urgency, and erectile dysfunction (Reipert, 2004). At this time preventive disease-modifying therapies (DMTs) are aimed at reducing the frequency and acuteness of attacks (Courtney et al., 2009; Wingerchuk, & Carter, 2014).

At present, there are 10 different DMTs offered as treatment options to individuals with relapsing forms of MS. The DMTs permitted include “First-Generation” Self-Injectable Therapies, which includes “Interferon beta 1a and 1b (IFNB), and Glatiramer acetate (GA), General Immunosuppression (Mitoxantrone), Natalizumab, and oral DMTs that include fingolimod, teriflunomide, and dimethyl fumarate/BG-12” (Wingerchuk, & Carter, 2014; p. 230). These medications work by suppressing the immune system at numerous different levels and with different action mechanisms. Additionally, these DMT’s have a favourable effect on RRMS, while they have no noteworthy beneficial effect on progressive MS subtypes (Gajofatto & Benedetti, 2015).

Since the presentation of MS differs from individual to individual, the response to current treatments also varies considerably. Through a process of mutual decision-making an individual with MS and their neurologist select an appropriate initial DMT. Recommendations for appropriate DMTs are made based on patient factors (drug harmfulness, drug acceptability, obedience to dose regime, and adherence to monitoring requirements), clinical factors (neurological damage, presence of neutralising antibodies, severity, recent attacks, and cognitive dysfunction), as well as MRI factors such as lesions evident on spinal cord and brain, development/deterioration of cerebral atrophy, and an increase of permanent axonal loss (Wingerchuk, & Carter, 2014).

2.9.1. Different treatment strategies

At present, there are two well-known treatment strategies often used by MS patients. These include sequential DMT monotherapy, and induction and maintenance strategy (Wingerchuk, & Carter, 2014). Research suggests that early treatment (both for physical and psychological symptoms) for MS is the best strategy, as MS related disability can accelerate in a short period of time (Fernandez et al., 2010). Additionally, results of a study by Wingerchuk and Carter (2014) indicated that the greatest lack with regards to MS treatment exists in that there are no any available therapies that slow the development of progressive forms of MS as well as the lack of treatment to repair damaged neurons, oligodendrocytes and supporting glia cells.

2.9.1.1. Physiological treatment

Sequential DMT monotherapy is currently the most common strategy. This treatment strategy starts patients with their first DMT treatment and involves an observation phase for clinical/MRI disease activity along with adherence, tolerability, and safety. This therapeutic strategy aims to produce prolonged clinical and radiological remission, without substantial adverse events. If this is accomplished, treatment will continue with periodic reassessment (Wingerchuk, & Carter, 2014).

The induction and maintenance strategy rely on the initial use of early and aggressive immunotherapy (such as IFNB, GA, teriflunomide and dimethyl fumarate) with the aim of preventing the development of a degenerative MS course. Once the patient is in remission, they transition to less aggressive immuno-modulatory therapies, such as natalizumab, alemtuzumab, and mitoxantrone (Gajofatto & Benedetti, 2015; Wingerchuk, & Carter, 2014). This therapeutic strategy is usually recommended to MS patients who experience severe and regular relapses and present with an amplified possibility for rapid disability (Gajofatto & Benedetti, 2015).

2.9.1.2. Psychological treatment

As mentioned previously in section 2.7, MS has a debilitating effect on various aspects (physical, psychological, and cognitive) of an individual's life (Fiest et al., 2016). With this being said, it is imperative that treatment is provided for the effect that MS has on an individual's mental health (such as MS-related fatigue, cognitive impairments, depression and anxiety) as well.

Research on the effect of depression amongst individuals diagnosed with MS has found that depression is related to breakdowns in interpersonal relationships and employment, increased cognitive impairment, increased risk for suicide, less adherence to medication, and lower QoL (Hind et al., 2014). The most popular treatment strategies used by individuals with MS (for symptoms such as MS-related fatigue, cognitive impairment, depression, anxiety) include cognitive behaviour therapy (CBT), group psychotherapy and antidepressant medication such as sertraline (Dehnavi, Heidarian, Ashtari, & Shaygannejad, 2015). A study by Van Mierlo et al. (2014) determined that psychological illnesses (such as depression and anxiety) caused by chronic illness could further negatively influence QoL as these factors contribute to the way in which people react to stressful situations.

It is therefore evident that these treatment strategies do provide some options and hope for those with less progressive MS, but individuals diagnosed with progressive forms of MS are left with several unmet needs with which they need to cope. It is apparent that a diagnosis of MS is accompanied with several complicated symptoms, which includes physical and psychological aspects (Wingerchuk, & Carter, 2014). These aspects shape and influence the way in which an individual copes with being diagnosed with MS, which will be discussed in the subsequent section.

2.10. The concept of coping

Extensive research has been done on coping and its influence on physical and mental health (Farran, Ammar, & Darwish, 2016; McCabe et al., 2004; Montel & Bungener, 2007). It has been established that stress affects physical and mental aspects of individuals, their performance and lifestyles. The methods people use to manage and cope with stress, have become of utmost importance in research (Ahadi, Delavar, & Rostami, 2014). Although many definitions and theories regarding coping are available (Dewe, 1987; Latack, 1986), the work of Lazarus and Folkman (1984) is most frequently used to conceptualise coping (Sanaeinasab et al., 2017). To demonstrate the applicability of coping on MS, certain theoretical concepts must be explained which will be done in the following paragraphs.

Lazarus and Folkman (1984) describe coping as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 110). This definition of coping is process-orientated, in that coping is defined as a behaviour or a set of responses that occur over time and is influenced by the interaction of environmental as well as personal factors (Lazarus & Folkman, 1984; Taylor, 2006). A process method of defining and understanding coping is made up of three main characteristics. Firstly, evaluations and observations - which concern what the individual actually thinks or does, as opposed to what the individual usually does. Secondly, what the individual thinks or does is evaluated within a particular setting, as Lazarus and Folkman (1984) argue that coping actions are continuously focused on specific conditions. To understand the way an individual copes, the context within which they are coping with needs to be known. The last characteristic addresses the notion of coping as a shifting process. This implies that coping thoughts and actions change as stressful encounters develop and the person-environment relationship changes (Lazarus & Folkman, 1984). Coping therefore becomes a sequence of transactions between an individual with a unique set of values, resources, and commitments as well as a precise environment with its own stresses, restraints, and resources (Taylor, 2006).

2.10.1. Coping strategies

As proposed by Lazarus and Folkman (1984), coping strategies can be divided into three categories namely those aimed at solving the problem, strategies that regulate emotions and those designed to avoid the problem. These categories are made up of specific strategies, namely planning, active coping, instrumental support (solving the problem), emotional support, venting, positive reframing, acceptance, humour, religion (strategies that regulate emotions), and behavioural disengagement, mental disengagement, denial, substance use, self-blame (avoidance coping). The strategy used by an individual to cope is influenced by their current and available resources. These resources include health and energy, beliefs (existential and general beliefs about control), problem solving abilities, social skills, commitments, material resources, and social support. Although these are three different strategies and can be utilised individually, they are often employed simultaneously (Lazarus & Folkman, 1984; Lazarus, 1999).

2.10.1.1. Coping strategies aimed at solving the problem

Coping strategies that centres on the problem designates attempts made to resolve a stressful circumstance/issue and are more likely to be used if the individual feels that the stressful circumstance/issue can be changed. This coping strategy comprises of efforts such as removing the source of stress, pursuing information in handling the situation, and removing oneself from the situation (Lazarus & Folkman, 1984; Lazarus, 1999).

Kahn, Wolfe, Quinn, Snoek, and Rosenthal (1964) identified two groups of problem-focused coping strategies, namely those directed at the environment and those directed at the self. Problem-focused coping strategies directed at the environment include strategies that aim to change environmental obstructions, stress, resources, and procedures. In contrast, problem-focused coping strategies directed at the self are focused on obtaining cognitive or motivational changes such as lessening ego involvement, finding alternate networks of gratification, developing new values of behaviour, and learning new skills (Kahn et al., 1964).

2.10.1.2. Coping strategies that regulate emotions

Coping strategies that focus on emotions represent the method of emotion regulation, where the individual decreases emotions caused by the stressful situation/issue without concentrating on the specific problem. This approach is more likely to be used when an individual has evaluated the stressful situation/issue and has concluded that nothing can be done to alter this (Lazarus & Folkman, 1984; Lazarus, 1999). These strategies include attempts such as isolation, avoidance, blame, minimalizing emotions, wishful thinking (hoping that your problem will go away without taking action), looking for social support, and meditation (Ahadi et al., 2014; Rice, 2000).

Coping strategies focused on emotion can also be grouped into two, specifically those directed at decreasing emotional distress and those directed at increasing emotional distress. Strategies targeted at decreasing emotional distress include avoidance, isolation, positive comparison, selective attention, and minimization. On the other hand, some individuals often employ strategies directed at increasing emotional distress, such as self-blame or self-punishment (Lazarus & Folkman, 1984).

2.10.1.3. Coping strategies of an avoidant nature

Coping strategies that focus on avoidance refer to indirect efforts aimed at adjusting to the stressor by avoiding the stressor or diminishing feelings related to the stressor (Eschenbeck et al., 2007). This includes efforts such as behavioural disengagement (detaching oneself from the self and the world) mental disengagement, denial, substance use, and self-blame (Lazarus & Folkman, 1984; Lazarus, 1999).

With such a large array of coping strategies, it often becomes difficult to assess what constitutes as successful coping. With this being said, Karatsoreos and McEwen (2011) established a list of outcomes that if achieved, constitutes successful coping. These outcomes include: decreasing or eliminating stressors; adjusting to negative events; upholding a positive self-image; sustaining emotional equilibrium; remaining in satisfying relationships; if one is ill, increasing the predictions of recovery; and maintaining physical, neuroendocrine, and immune reactivity fairly low or returning these systems to pre-stress levels (Karatsoreos & McEwen, 2011).

2.10.2. Coping with multiple sclerosis

MS not only negatively influences the physical capabilities of those diagnosed, but other MS-related problems include decreased productivity, challenges in personal and social relationships, and psychological illnesses such as depression and anxiety (Farran et al., 2016). Individuals with MS need to cope with its uncertain nature, changing social relationships, and increased needs for support, which often leads to irregular episodes of deteriorating health (McCabe et al., 2004). Additionally, research by Kar, Whitehead, and Smith (2017) found that the process of adapting to a chronic disease such as MS rests on the effectiveness of coping, which in turn moderates the process of adjustment to MS and psychological well-being.

2.10.2.1. Coping strategies used by individuals with MS

Although there are periods where individuals living with MS are somewhat symptom- free, the coping strategies they use differ from the general healthy population (Goretti et al., 2009). Studies have shown that individuals with MS use certain coping strategies less often than the general population. For example, in a study by McCabe and McKern (2002) the authors demonstrated that compared to a sample from the general population, individuals with MS seldom use coping strategies such as task-orientation and a positive attitude, whereas the general population use these problem directed strategies frequently. Goretti et al. (2010) also reported that the MS population more frequently use detachment and coping strategies such as denial, mental and behavioural disengagement. A study by Ožura and Šega (2013) found that individuals with MS also tend to display a decreased ability for coping with everyday stresses when compared to healthy individuals.

More specifically, in a recent study by Ahadi et al. (2016) the authors demonstrated that individuals with MS use all types of coping strategies at some point in time. However, research on coping with MS indicates that the majority of these individuals are more likely to use coping strategies such as venting, isolation, self-blame, selective attention, and minimization to cope with MS (Farran et al., 2016; Goretti et al., 2010, Kar et al., 2017; McCabe et al., 2004; Montel & Bungener, 2007; Tan-Kristanto & Kiropoulos, 2015). For example, in the study by Tan-Kristanto and Kiropoulos (2015) the authors found that individuals with MS used venting and substance use as coping strategies more than they did strategies such as seeking social support for instrumental reasons. Coping strategies such as humour and religion are often employed by individuals with MS in the early stages of the illness and are also related to exacerbations of symptoms. Coping strategies in which the problem is avoided (such as self-blame and denial) are often used when the source of stress is unclear, and when an individual can do little to lessen/remove the stressor (Farran et al., 2016). In contrast, in a study by Lode et al. (2007) the authors indicated that coping strategies directed at the problem (such as seeking social support and planning) are more often used if the individual has been living with MS for several years and has experienced its disabling symptoms. The use of such coping strategies can be attributed to the fact that these individuals have grown accustomed to living with MS and are more adjusted than those who are newly diagnosed (Lode et al., 2007).

2.10.3. Factors influencing coping amongst MS individuals

Extensive research (Arnett et al., 2002; Goretti et al., 2009; McCabe et al., 2004; McCabe& DiBattista, 2004; Montel & Bungener, 2007) has been done to explain the different coping strategies employed by MS patients. Following a systematic review by Kar et al. (2017) of these studies (Arnett et al., 2002; Goretti et al., 2009; McCabe et al., 2004; McCabe& DiBattista, 2004; Montel & Bungener, 2007) a list of factors that influence coping with MS was compiled. These factors are categorized into individual characteristics (gender, level of education, age and employment status), clinical features (disability due to MS, clinical course, and disease duration), and psychological factors (mood status, self-esteem, and attitude).

2.10.3.1. Individual characteristics

Since the majority of individuals diagnosed with MS are female, it is no surprise that gender differences have also been found in coping with MS. Research suggests that women tend to use coping strategies such as diversion, detachment, seeking social support, and focussing on the positive, while men are more prone to use coping strategies such as planning and active coping (Kar et al., 2017; Mikula et al., 2014). Additionally, women who have children report the use of more positive coping strategies, such as religious belief and searching for a sense in life

(Twork, Wirtz, Schipper, Klewer, Bergmann, & Kugler, 2007). Level of education has also been found to impact the type of coping strategies used by individuals with MS. For example, in a study by Goretti et al. (2009) individuals with a higher level of education (such as tertiary education) use coping strategies such as social support more often and more effectively than those with a lower level of education. Another factor that has been researched as having an influence on coping with MS is age. For example, a study by Jones and Amtmann (2015) found that individuals with MS are better able to cope with physical changes as they age. This may be due to the fact that these individuals age they may have developed more ways to cope with and live with the symptoms of MS compared to younger adults (Jones & Amtmann, 2015). Lastly, employment status is also regarded as having an influence on coping with MS (Strober & Arnett, 2016). Research indicates that individuals with MS who have had to leave work due to the illness are more likely to use coping strategies such as behavioural disengagement and substance use (Strober & Arnett, 2016).

2.10.3.2. Clinical features

Research indicates that individuals living with greater disability as a result of MS are more prone to use coping strategies such as avoidance, venting, and mental and behavioural disengagement (Lode, Bru, Klevan, Myhr, Nyland, & Larsen, 2010). Additionally, the clinical course also influences coping patterns. Individuals with a relapse-remitting course use coping strategies such as voicing of emotions, behavioural detachment, and mental detachment less often in comparison to those with a secondary-progressive course who are prone to use social support, acceptance and denial as coping strategies (Goretti et al., 2009). When individuals with MS suffer disease exacerbations, a larger number of daily complications and emotional distress are reported, which could explain the increased use of coping strategies such as denial, acceptance, behavioural detachment, and mental detachment intended to lessen emotional anguish (Lode et al., 2007; McCabe et al., 2003). Mikula et al. (2014) contends that the use of coping strategies that include denial, acceptance, behavioural detachment, and mental detachment amid individuals with MS can be accredited to the feeling of having less control (over their health and lives) due to MS and trying to regain control by managing distressing emotions. The last clinical feature, disease duration, also severely influences coping strategies. In the studies by Goretti et al. (2009) and Montel and Bungener (2007) the authors respectively state that individuals with a shorter disease duration are inclined to employ a less positive attitude towards coping with MS.

2.10.3.3. Psychological factors

Depression and anxiety amongst individuals with MS have been related to the increased use of coping strategies such as behavioural and mental disengagement, denial, substance abuse, and self-blame (Lode et al., 2009; Farran et al., 2016). Attitude has also been linked to coping patterns amongst individuals with MS (Farran et al., 2016). For example, De Ridder, Schreurs and Bensing (2000) found that individuals who are optimistic tend to use behavioural and mental disengagement, denial, substance abuse, and self-blame less while individuals who are pessimistic rely more on such coping strategies. Moreover, a lack of self-esteem has also been linked to the tendency of relying more on coping strategies such as denial, substance abuse, and self-blame while those with a high self-esteem use active coping, planning, and seeking of instrumental social support as a way of coping (Farran et al., 2016).

Coping with MS therefore depends on an array of factors, and coping strategies will not necessarily stay constant as time passes. The findings of the systematic review by Kar et al. (2017) indicates that individuals with MS use different coping strategies during the different stages of the illness. The early stages of MS (just after receiving a diagnosis up until 4 years of being diagnosed) are related to the use of less active coping strategies such as emotion directed and avoidant coping strategies. The transition to more progressive MS types (PPMS, SPMS, and PRMS) often results in the use of coping strategies such as avoidance, denial, substance abuse, and self-blame. As time passes coping strategies such as active coping, planning, and seeking of instrumental social support are employed (Kar et al., 2017; Lassmann, 2013).

2.10.4. Effect of coping on well-being

Lazarus (1993) argues that no coping strategy is completely good or bad, although some coping strategies might be more or less helpful than others. He further states that, in determining which coping strategy is better or worse, one must take into account "the particular person, the specific type of encounter, in the short or long run, and the outcome modality being studied" (Lazarus, 1993; p. 235). With this being said, research by Lazarus and Folkman (1987) on coping and its relationship to well-being has indicated that a relationship exists between coping and psychological symptoms. They ascertained that coping strategies such as active coping, planning, and seeking of instrumental social support are often associated with less psychological troubles, while coping strategies such as distancing and avoidance are often related to symptoms of depression and anxiety.

Moreover, literature on coping with MS suggests that active coping, planning, and seeking of instrumental social support are more beneficial, as these strategies are generally associated with improved adjustment, reduced distress, higher life satisfaction and overall better QoL (Lode et al., 2007). A systematic review by Kar et al. (2017) ascertained that coping effectively with MS has an influence on disease activity (symptom exacerbation), and treatment behaviour. With regards to symptom exacerbation, the use of coping strategies such as active coping and planning been found to moderate the frequency of relapses. Additionally, this type of active coping is found to increase the likelihood of starting and adhering to treatment (Kar et al., 2017).

In line with the literature, research on the use of coping strategies such as denial, self-blame, substance use, and disengagement among individuals with MS indicates that these strategies are often related to poor adjustment, increased stress, and elevated levels of psychological distress, including depression and anxiety. Additionally, the use of denial, self-blame and substance use as coping strategies has been linked to an increase in relapses as well as decreasing the likelihood of individuals newly diagnosed with MS to start treatment (Kar et al., 2017). A recent study by Kristofferzon, Engström, and Nilsson (2018) found that utilised coping strategies (perceived as effective) by individuals with chronic illnesses have a positive effect on their QoL. It is therefore evident that the coping strategies used by individuals with MS have a significant effect on their well-being as well as overall QoL, which will be discussed in detail in the subsequent section.

2.11. Quality of life (QoL)

2.11.1. Defining quality of life

QoL is a comprehensive concept that refers to an individual’s outlook on their level of fulfilment concerning various aspects of well-being, and embraces emotional, social, cultural and economic aspects (Benito-León et al., 2003; Price & Harding, 1993). The WHOQOL Group (1994) defines QoL as

> Individual’s perceptions of their position in life in the context of the culture and value system where they live, and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, incorporating in a complex way a person’s physical health,

> psychological state, level of independence, social relationships, personal beliefs and relationship to salient features of the environment (p. 1405).

This definition stresses that QoL refers to a subjective appraisal, which induces positive and negative dimensions, and is fixed in a cultural, social and environmental context (World Health Organization Quality of Life [WHOQOL] Group, 1994). Similarly, McCabe and McKern (2002) draw a distinction between the two types of QoL, namely objective and subjective QoL. Objective QoL refers to the real, quantifiable situation relative to a specific area (i.e. income), while subjective QoL denotes an individual's level of satisfaction with a specific area (i.e. satisfaction with income).

Lobentanz et al. (2004) identified a list of four uses of QoL in healthcare The concept of QoL is used for the individual formation of clinical care for patients; in health research and clinical trials as an outcome measure; for health necessities assessments of populaces, and for the provision of resources (Lobentanz et al., 2004). QoL has therefore become a central concept in research evaluating the impact a chronic illness such as MS has on an individual (Shawaryn, Schiaffino, LaRocca, & Johnston, 2002).

2.11.2. QoL in the MS population

Based upon the fact that MS is a disease affecting the CNS, a deterioration of several health-related aspects consequently follows. Since the progression of MS is irregular, it often happens that individuals with MS are uncertain about what the future course of the illness holds. Considering the profile of MS, it is not surprising that it has a considerable influence of the QoL of individuals diagnosed with it (McCabe & McKern, 2002).

Literature on QoL amongst individuals with MS suggest that, in comparison to the general population, QoL is lower amongst the MS population (Janardhan & Bakshi, 2002; Kes et al., 2013; McCabe & McKern, 2002). Additionally, in a study by McCabe and McKern (2002) the authors found that individuals with MS encounter impaired QoL on both objective and subjective levels, especially in the areas of psychological performance, characteristics of the environment, and social relationships. Moreover, it has been established that functional disability due to disease-related factors can only partially explain the impaired QoL amongst the MS population. It is therefore evident that there are other factors that also severely influence the QoL of individuals diagnosed with MS, which should be explored (Cioncoloni et al., 2014; Papuć, & Stelmasiak, 2012).

2.11.3. Factors influencing QoL of individuals with MS

The lower levels of QoL amongst individuals with MS is maintained to be ascribed to particular features of MS such as the fact that MS usually starts during the productive days of one’s life, the unstable character of MS, the physical and social limitations due to CNS damage, and the absence of a cure (Motl et al., 2013). Moreover, the factors that substantially influence MS individuals’ QoL negatively can be divided into three domains, namely physical, psychological, and social. These domains are made up of different aspects, which all contribute to QoL in different ways (Füvesi et al., 2010; Kes et al., 2013).

2.11.3.1. Physical domain

MS-related physical symptoms have been found to substantially affect individuals’ QoL. Research indicates that a poor QoL is related to a progressive disease course, physical disability due to MS, fatigue, reduced mobility, cognitive impairment, and pain (Füvesi et al., 2010; Kes et al., 2013; McCabe & McKern, 2002; Mitchell et al., 2005).

Of these aspects, fatigue has been found to be a significant contributor of a reduced QoL. The frequency of fatigue in MS has also been increasing, with approximately 80 % of individuals with MS suffering from fatigue. What makes these symptoms so troubling is the fact that it affects an individual physically and psychologically and has also been found to contribute to the development of depression (Kes et al., 2013; Lobentanz et al., 2004; Mitchell et al., 2005). The intensity of the disease course is also said to have an impact on an individuals' QoL, with a more intense disease course relating to a worse QoL (Benito-León et al., 2003). Furthermore, the rate of cognitive impairment amongst individuals with MS ranges from 30-70 %. This impairment has a substantial negative effect on an individual's QoL since cognitive impairment (attention, memory, information processing speed, executive function etc.) in conjunction to the aforementioned physical disabilities, lead to less autonomy and lesser life-satisfaction (Füvesi et al., 2010; Kes et al., 2013). Additionally, QoL in South Africa is further influenced by certain other factors such as contextual, social, political and economic factors that may exacerbate MS patient experiences and influence how they cope with MS.

2.11.3.2. Psychological domain

As previously mentioned, depression is one of the foremost psychological contributions to a reduced QoL, with a prevalence rate of 42 % to 54 % (Kes et al., 2013; Lobentanz et al., 2004). In a study by Amato et al. (2001) the authors argue that the development of depression in the MS population is either due to the individuals' reaction to MS (disability and symptoms), or from the disease process itself. Furthermore, a study by Mitchell et al. (2005) classified a list of psychological-related aspects that are potential predictors of diminished QoL amongst individuals with MS. These predictors include emotion-focused coping strategies (especially avoidance and wishful thinking i.e. hoping that your problem will go away without acting), depression, feeling hopeless, lack of independence, anxiety, and low self-esteem (Mitchell et al., 2005).

2.10.3.1. Social domain

The social factors that affect QoL in the MS population includes, social support, social participation, and employment (Mitchell et al., 2005). Social participation has been linked to increased self-esteem, mental health status, and life satisfaction (Mikula et al., 2014). A study by Farran et al. (2016) found that individuals with less social support (such as reaching out to friends/family/co-workers and forming community ties) tend to report a poorer QoL. A correlation between employment and QoL has also been found, with unemployed individuals often reporting poorer QoL when compared to employed counterparts (Papuć & Stelmasiak, 2012). Individuals with adequate social support systems therefore exhibit a better QoL (Ledesma et al., 2018).

2.12. The relationship between coping and QoL

As mentioned previously, MS is a chronic disease, which results in lower levels of QoL when compared to healthy controls, as well as individuals suffering from other chronic diseases, such as diabetes (Motl et al., 2013). Wide-ranging research has been performed on the effect of coping and different coping strategies on one's mental health and QoL (e.g. Farran et al., 2016; Goretti et al., 2009; Goretti et al., 2010; McCabe et al., 2004; Mitchell et al., 2005). Several researchers have examined the association between coping and MS and have correspondingly found that coping strategies are important predictors of QoL (McCabe et al., 2004; Montel & Bungener, 2007; Ledesma et al., 2018; Lode et al., 2007; Plow et al., 2009; Sanaeinasab et al., 2017).

Literature on coping suggests that it often happens that when health problems occur, individuals tend to use coping strategies such as self-blame, substance use, denial, and positive reinterpretation. The reliance on these coping strategies could perhaps be due to the fact that health problems are not responsive to direct action, and therefore need to be tolerated (Kar et al., 2017). Correspondingly, studies on coping with chronic illnesses have found that individuals with chronic illnesses (such as asthma, chronic kidney disease, and chronic pain) generally rely on coping strategies such as substance use, denial, positive reinterpretation, and disengagement. These coping strategies have also been found to correlate with a poorer QoL and worse psychological adjustment (Gemmell et al., 2016; Hesselink et al., 2004; Yetwin et al., 2018). Research on coping with MS also indicates that individuals with MS tend to use substance use, self-blame, denial, positive reinterpretation, and disengagement as coping strategies more often (Farran et al., 2016; Goretti et al., 2009; Goretti et al., 2010).

Coping strategies such as behavioural disengagement, wishful thinking (hoping that your problem will go away without taking action), and self-accusation have been found to correlate with a poorer QoL (Farran et al., 2016; Goretti et al., 2009; Goretti et al., 2010; Montel & Bungener, 2007). Additionally, research by Farran et al. (2016) as well as Montel and Bungener (2007) respectively discovered that individuals with MS using coping strategies (such as denial) are more likely to encounter greater levels of distress, worse psychological adjustment, fatigue, and psychological illnesses, such as depression and anxiety. Moreover, wishful thinking has been widely recognised as a maladaptive coping strategy, as it has consistently been related with poor psychological adjustment, and higher levels of depression (Farran et al., 2016; McCabe et al., 2003). Additionally, ineffective coping has also been related to an increase in MS and symptom exacerbations (Kar et al., 2017).

Mikula et al. (2014) offer an explanation for the reliance on substance use, self-blame, denial, positive reinterpretation, mental – and behavioural disengagement as coping strategies amongst individuals with MS. They argue that these individuals use these strategies to stop the unpleasant emotions and/or thoughts given that they have little control over their illness (Mikula et al., 2014). The study by Montel and Bungener (2007) also identified that the type of MS effects individuals' QoL, with the poorest QoL evaluations found amongst individuals with SPMS and the best for PPMS, which is due to the intensity of symptoms associated with this type of MS.

In contrast, a positive relationship between coping strategies such as emotional support, a positive attitude, planning and improved QoL has been stated (Farran et al., 2016; Ledesma et al., 2018). Research by Goretti et al. (2010) and Mikula et al. (2014) respectively found that when these coping strategies (emotional support, a positive attitude, planning) are used, enhanced adjustment, higher life satisfaction, reduced distress towards MS, and overall improved mental health is experienced.

These studies highlight the fact that patients with MS should be encouraged to rather use healthy coping strategies, such as emotional support, a positive attitude, planning, which are associated with an improved QoL. Adjusting therapeutic interventions towards creating and enhancing coping strategies used by individuals with MS could help enable them to better deal with the demands of the illness. (Goretti et al., 2010; McCabe et al., 2004; Montel & Bungener, 2007; Plow et al., 2009; Sanaeinasab et al., 2017). It can consequently be hypothesized that an individual's coping style could play an imperative role in his/her QoL. The primary aim of this study is therefore to determine if a relationship exists between the coping strategies used by individuals with MS and their QoL.

2.13. Conclusion

In this chapter I provided contextual information regarding MS and important MS-related research. It is apparent from the literature review that research on MS within the South African context is scant, with only two studies found. Coping with MS, and the coping strategies often used by individuals with MS were discussed. Moreover, it was ascertained that individuals with MS have poorer QoL in comparison to the general population. It is therefore evident that MS is an important health concern that has a negative effect on the QoL of those diagnosed. Lastly, this chapter also highlighted the relationship between coping strategies and QoL, which included the effect that certain coping strategies have on an individuals' QoL. In the following chapter I will discuss the theoretical framework that is used to conceptualize this study.

Chapter 3

Theoretical framework

3.1. Introduction

In this chapter I discuss the theoretical framework used to guide this study, namely Lazarus and Folkman’s (1984; 1987) transactional theory of stress and coping (TTSC). I discuss the main concepts that form the basis of the transactional theory of stress and coping in detail. These concepts include environmental and personal variables, mediating processes (cognitive appraisal and coping), and adaptational outcomes. Furthermore, I will also discuss critique on this theory. I will conclude this chapter with a discussion of the relevance of Lazarus and Folkman’s (1984; 1987) transactional theory of stress and coping with regards to coping with MS.

3.2. The transactional theory of stress and coping

Lazarus and Folkman’s transactional theory of stress and coping postulates that stress is a transaction between a person and the environment. This transaction is then evaluated by the person as demanding or surpassing his or her resources and as threatening their well-being (Lazaurus, 1966; Lazarus & Folkman, 1984). In this model the authors argue that stress is a two-way process. Stress involves the construction of stressors by the environment, and the response of an individual subjected to these stressors. Stress therefore does not exist in the event (an encounter with the environment) itself, but that it is the outcome of a transaction between an individual and their environment (Lazarus, 1966). This process involves unwanted/adverse person-environment relationships, cognitive assessments (appraisals) of the situation, and emotional response states such as anger, guilt, distress, and embarrassment. Emotions, especially those considered to be related to stress (anxiety, fear, anger, guilt, etc.), form a central part of this transactional model as these in turn affect thought processes. Stress is therefore described as a relationship between the person and their environment, which is assessed by the individual as either challenging or surpassing his/her resources and jeopardizing his/her well-being. That which occurs during the course of appraisal, determines what emotions and coping behaviours will follow (Lazarus & Folkman, 1984). With regards to coping, the TTSC recognizes that everyone will cope in a different way with the challenges they encounter. This is due to the fact that coping behaviours are created on the interaction between a stressful situation and an individuals' environment, which is then arbitrated by cognitive appraisal (Sanaeinasab et al., 2017).

With their TTSC, Lazarus and Folkman (1984) create an association between stress-related variables and outcomes related to health and well-being. That is to say that "the quality of life and what we usually mean by mental and physical health are tied up with the ways people evaluate and cope with the stresses of living" (Lazarus & Folkman, 1984, p. 181). Furthermore, Lazarus and Folkman (1984) identified five key variables on which their transactional theory is based and will be discussed in detail in the following sections. These variables include stress, appraisal, coping, person and environment antecedents of stress and coping, as well as short- and long-term adaptational outcomes. For descriptive purposes, an amended theoretical schematization of the TTSC is presented in Figure 3.1.

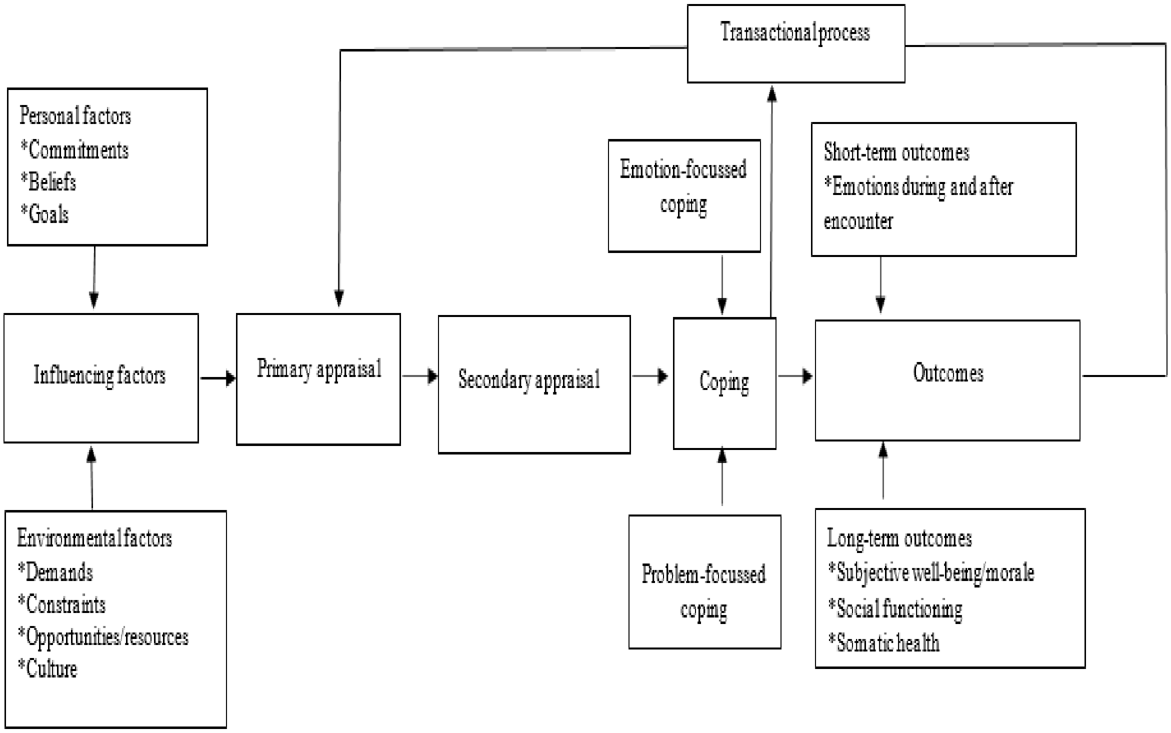

Figure 3.1. Amended schematic representation of the transactional theory of stress and coping (based on Lazarus & Folkman, 1984; Lazarus, 1966).

3.3. Environmental and personal variables affecting stress

As seen in Figure 1, Lazarus (1999) identified four environmental variables that effect emotion and stress. These include demands, constraints, opportunities, and culture. These variables then interact with personal variables (commitments, beliefs, and goals), which influence our responses through the process of appraisal (Lazarus, 1999).

The first of the environmental variables is demands. Demands are implied or overt burdens from an individuals' social environment that act in a specific way and have specific social attitudes. These demands often collide with our inner beliefs and goals, causing psychological stress. The second variable, constraints, outlines what individuals should not do (such as defying the social standards by coping in a certain manner with a stressful event) and are often followed by punishment (such as disapproval or being outcast from the group) if dishonoured. The third variable, opportunity, often occurs due to lucky timing, but could also be due to knowledge in identifying opportunities. These include efforts such as placing oneself in the best social and work position to increase favourable outcomes. Lastly, culture and the manner in which an individual was brought up also plays a role in how stress and emotions are experienced (Lazarus, 1999).

Figure 1 also highlights the personal variables that play a role in the experience of emotions and stress, which include goals and goal hierarchies, beliefs about oneself and the world, and personal resources (Lazarus, 1999). The first variable, goals and goal hierarchies, refer to what is important to us as well as what we value most and least. These are important as emotions due to stress develop if there is a likelihood that an event will stop the person from realizing his/her goal. The second variable, beliefs about oneself and the world, represent how we perceive ourselves and our place in society, which also influences our expectations. The last variable, personal resources refer to the means we possess and are able to pursue in order to realize needs, achieve goals and cope with the accompanying stress created by the environmental variables- demands, constraints, and opportunities (Lazarus, 1999).

3.4. Mediating processes

Two critical mediators that form part of Lazarus and Folkman's (1984; 1987) transactional theory of stress and coping are the processes of cognitive appraisal and coping, as noted in Figure 1. These processes are transactional variables, implying that they do not refer to the person or the environment on its own, but to the combination of both in a specific transaction (Folkman, Lazarus, Gruen, DeLongis, 1986).

3.4.1. Cognitive appraisal

Cognitive appraisal denotes the procedure of assessing an encounter and its numerous aspects, with respect to the implication for the individuals' well-being. Furthermore, how an individual appraises a situation is influenced by two determinants, namely commitments (what is important to an individual) and beliefs (personally shaped or culturally shared cognitive alignments). Commitments and beliefs influence appraisals by determining what is significant for well-being in a specific encounter, they shape an individual's grasp of a specific encounter, and they act as a foundation for appraising consequences. With this being said, three types of appraisal are identified, namely primary appraisal, secondary appraisal, and reappraisal (Lazarus & Folkman, 1984).

Primary appraisal signifies a decision made about what an individual understands a situation to hold in store for them. This embodies a process of assessing what the possible effect of demands and resources are on an individual's well-being and if a stress reaction is necessary (Lyon, 2000). Additionally, Lazarus & Folkman (1984) distinguish between three kinds of primary appraisal, that is irrelevant, benign-positive, and stressful. A situation can be regarded as irrelevant if it has no implications for an individual's well-being. Benign-positive appraisals ensue when an encounters' outcome is interpreted as positive, in other words enhancing or preserving the individual's well-being. When an encounter is perceived a stressful, it can fall three categories into, specifically harm, threat and challenge. Harm denotes something that has already been experienced, threat indicates a potential for harm/anticipated harm, and challenge refers to the prospective mastery of the hindrance.

Primary appraisal is supplemented by secondary appraisal, which represents a complex procedure of assessing what can be done about the stressful situation (Lazarus & Folkman, 1987). This involves assessing which coping behaviours are available, the likelihood of the coping behaviour accomplishing what it is supposed to, and the likelihood that one can apply the coping behaviour effectively. Lastly, reappraisal refers to the process of constantly evaluating, changing or relabelling previous appraisal based on new information as the situation changes (Lazarus & Folkman, 1984; 1987).

3.4.2. Coping

In agreement with the TTSC, coping is described as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). A process method to defining and understanding coping is made up of three main characteristics. Firstly, evaluations and observations concern what the individual truly thinks or does, as opposed to what the individual typically does. Secondly, what the individual thinks or does is evaluated within a particular context, as Lazarus and Folkman (1984) argue that coping actions are continuously focused on specific conditions. In order to understand how an individual cope, the context of what they are coping with needs to be known. The last characteristic addresses the notion of coping as a shifting process. This implies that coping thoughts and actions change as stressful encounters develop and the person-environment relationship changes (Lazarus & Folkman, 1984). Coping therefore becomes a sequence of transactions between an individual with a unique set of values, resources, and commitments as well as a precise environment with its own stresses, restraints, and resources (Taylor, 2006).

As discussed in section 2.10, Lazarus (1993; 1999) identified that coping has two major functions, namely, problem-focused and emotion-focused. The function of problem-focused coping is to alter the stressful person-environment relationship by acting on either the environment or yourself. In contrast emotion-focused coping aims to reduce the emotions caused by the stressful situation (Lazarus, 1993). Lazarus and Folkman (1984) further state that encounters that are judged as necessitating acceptance are often associated with a greater use of emotion-focused coping strategies, while encounters where an individual deemed action necessary a greater importance was placed on problem-focused coping strategies. Regardless of how cognitive appraisal and coping are theorized, the primary importance of these processes is that they shape adaptational outcomes (Lazarus & Folkman, 1984).

3.5. Adaptational outcomes

In order to rate the efficiency of specific coping efforts Lazarus and Folkman (1984) identified three types of outcomes, each comprising of short-term (right after the encounter) and long-term effects. As seen in Figure 1, these adaptational outcomes include functioning in work and social living (social functioning), morale/life satisfaction, and somatic health (Lazarus & Folkman, 1984).

The first outcome, functioning in work and social living, is described as the way in which a person accomplishes his/her numerous roles, for examples a spouse, parent, jobholder. The short-term outcome relates to the quality of a person's social functioning and is ascertained by how efficient day-to-day events are managed. The effectiveness of a coping strategy therefore depends upon how appropriate it is in terms of the internal/external demands of the specific situation. Similarly, long-term social functioning is an extension of the notion of coping effectiveness during the course specific events throughout an individual's life. For example, in order for an individual to have decent general functioning, the way a situation is appraised and coped with must at least tend to correspond the course of events (Lazarus & Folkman, 1984).

Morale or life satisfaction is described as how an individual feel about themselves as well as their life conditions and is often related to happiness, contentment and subjective well-being (Lazarus & Folkman, 1984). Here the short-term outcome is the positive and negative emotions that an individual experience during a specific encounter as these reflect the individual's brief assessment of this/her well-being at that moment. The long-term counterpart is dependent on performance outcomes as well as anticipations regarding the performance outcome. For example, it is more probable for individuals with lower expectations to interpret their performance with approval/satisfaction in comparison to those with higher expectations. Additionally, an individual that is satisfied with whether performance will ultimately have a positive sense of well-being (Lazarus & Folkman, 1984).

The last outcome, somatic health, relates to the notion that stress, emotions, and coping are underlying factors in health and illness. The short-term outcomes in somatic health has to do with the physiological response to the stressful encounter (e.g. increased heartrate). The long-term effects of how coping can adversely affect somatic health are three-fold. Firstly, the occurrence, strength, extent, and patterning of neurochemical stress reactions can be impacted by coping. This can occur through the manifestation of standards and an equivalent way of life "and/or coping style that in itself is consistently mobilizing in a harmful way" (Lazarus & Folkman, 1984, p. 215). Secondly, the risk of death and illness is increased when coping efforts involve the extreme use of harmful substances (such as alcohol, drugs, and tobacco) or when it implicates high-risk activities. Lastly, emotion-focused coping strategies (such as denial and avoidance) could possibly harm an individuals' health by hindering adaptive health-related behaviour (Lazarus & Folkman, 1984).

3.6. Critique against the transactional theory of stress and coping

Although a review of literature (Biggs, Brough, & Drummond, 2017; Goh, Sawang, & Oei, 2010; Laubmeier, Zakowski, & Bair, 2004; Rafferty & Griffin, 2006) alluded that this theory is considered the most appropriate for a study on coping, it is not without its critique. Lazarus and Folkman (1987) note that this approach has an important drawback. The transactional theory of stress and coping is process oriented as it focusses on describing coping in a specific context (which is affected by certain resources, demands, and constraints). Since coping in this theory is regarded as being a process "it runs the danger of being too contextual at the expense of the big picture, the overall coordinated strategies a person employs in dealing with" (Lazarus, 1999; p.117). This could attract our attention away from an individual's general style of coping, which makes it more difficult to study the consequences of stressful encounters in the long run (Lazarus, 1999). Furthermore, Aldwin (2007) and Lazarus (1990) respectively argue that this theory's view of stress and coping has further consequences concerning stress measurement. The TTSC is seen as a fluid system analysis, which is made up of many variables that can influence each other across time and changing context. This theory therefore forsakes a "simple input-output analysis" of stress and coping (Lazarus, 1990; p.4).

3.7. Theory related to MS

This framework has been chosen to conceptualise coping amongst individuals with MS based on four reasons. Firstly, the framework acknowledges that there are individual differences in coping behaviour. Secondly, the framework considers that coping strategies are determined based on the person-environment relationship. Thirdly, the framework recognises that coping strategies influence an individual's health (physical and psychological). Lastly, the framework was chosen since one of the questionnaires (Brief Cope) used in this study is based on the principles of the framework. These reasons will be discussed in the following paragraphs.

Coping with a serious illness such as MS needs to be comprehended through a comprehensive underlying theory such as Lazarus and Folkman's (1984) TTSC. This theory acknowledges that coping behaviours will differ amongst individuals as environmental (demands, constraints, opportunities, culture) and personal (goals, beliefs about oneself and the world, personal resources) variables are bound to differ, and therefor the capability of an individual to handle a stressful situation will be at variance (Lazarus & Folkman, 1984).

As discussed previously, coping is described as a sequence of transactions between an individual and a precise environment with its own stresses, restraints, and resources (Taylor, 2006). The TTSC concedes that everyone will cope differently with the challenges they face as coping behaviours are centred on the interaction between the stressful situation and their environment, which is then mediated by cognitive appraisal (Sanaeinasab et al., 2017). As discussed in the literature review, individuals with MS need to cope with its uncertain nature and symptoms varying in intensity, which frequently leads to unpredictable periods of declining health (McCabe et al., 2004). Moreover, this theory recognizes that coping behaviour is reliant upon situational triggers and stressors. In other words, when individuals with MS experience unpredictable periods of deteriorating health, their coping behaviours are bound to be different in comparison to periods when they are healthier (Pakenham, 2001; Sanaeinasab et al., 2017).

This leads to the next point, which involves the relationship between coping and health as acknowledged in the TTSC. In accordance with this theory, it is possible that individuals diagnosed with a disease (such as MS) perceive their situation as intolerably stressful and overwhelming since MS has no known cause; it leads to unpredictable periods of deteriorating health, and the fact that there is no cure (Farran et al., 2016; McCabe et al., 2004; Wingerchuk, & Carter, 2014). Based on this framework it can be predicted that these individuals would rely more on emotion-focused coping strategies (such as avoidance, wishful thinking, distancing), which is in fact widely reported in research (Farran et al., 2016; Goretti et al., 2010, Kar et al., 2017; McCabe et al., 2004; Montel & Bungener, 2007). The use of these maladaptive coping strategies negatively affects the health and QoL of individuals with MS as described in depth in section 2.8.4 and 2.9. In addition, a recent study by Sanaeinasab et al. (2017) on women with MS found that by applying a transactional model-based teaching program (on these women with MS) levels of stress could be lowered, and healthy coping behaviours increased.

The coping strategies questionnaire (Brief Cope), which will be used in this study is based on the principles of coping as described by Lazarus and Folkman (1984). It is therefore evident that by using the TTSC model as a framework to understand the underlying coping behaviours of individuals with MS, healthy coping behaviours that are beneficial to one’s QoL could be identified (Pakenham, 2001; Plow et al., 2009; Sanaeinasab et al., 2017).

3.8. Conclusion

In this chapter I discussed in detail Lazarus and Folkman’s (1984; 1987) transactional theory of stress and coping (TTSC). The major components and key concepts where defined and described. A schematic representation of this model was also presented. Furthermore, I discussed the critique of the transactional theory of stress and coping and highlighted the use of the theory in the context of this specific study. I will discuss the methodology of this study in the following chapter.

Chapter 4

Research methodology

4.1. Introduction

In this chapter, I present a detailed description of the research methodology used in this study. I list and discuss the research aims, questions and hypotheses. I then also discuss the research design used for this study. In this chapter, I will also include a detailed discussion of the various stages of the research, which includes participants and recruitment procedure, data collection (materials and procedures), as well as data analysis of this study. I conclude this chapter with the ethical considerations of the present study.

4.2. Research aim and objectives

The primary aim of this study was to determine the relationship between the coping strategies used by people with MS and their QoL in the context of South Africa. For this aim to be achieved, the following research questions were identified:

4.2.1. Is there a relationship between the coping strategies used by individuals with MS and their QoL?

4.2.2. Do males and females differ in terms of coping strategies used, and is this difference significant?

4.2.3. Do MS sub-types differ in terms of coping strategies used, and is this difference significant?

4.2.4. Do males and females differ in terms of overall QoL score, and is this difference significant?

4.2.5. Do MS sub-types differ in terms of overall QoL score, and is this difference significant?

4.2.6. Do biographical factors (such as gender, age, employment, relationship status), clinical factors (MS sub-type), and coping strategies (Brief cope sub-scales) have an influence on the QoL of individuals with MS?

4.3. Hypotheses

I tested five hypotheses in this study. Firstly, I hypothesised that a significant relationship will exist between the coping strategies used by individuals with MS and their levels of QoL. Specifically, I hypothesised that individuals with MS who use planning, active coping, emotional support, positive reframing, and instrumental support will report significantly higher levels of QOL than those who use other styles of coping.

Secondly, I hypothesised that females with MS would score significantly higher on coping strategies such as detachment, seeking social support, and focussing on the positive than males.

Thirdly, I hypothesised that those with SPMS and PRMS MS sub-types would score significantly higher on coping strategies such as behavioural disengagement, mental disengagement, denial, substance use, self-blame, than those with RRMS and PPMS MS sub-types.

Fourthly, I hypothesised that females with MS would report significantly higher QoL levels than males. Fifthly, I hypothesised that individuals with SPMS and PRMS MS sub-types would report significantly lower levels of QoL (global index score <63.83) than those with RRMS and PPMS MS sub-types.

Lastly, I hypothesised that there will be a significant prediction of QoL scores by biographical factors (gender, age, employment, and relationship status), MS sub-type (RRMS, PPMS, SPMS, PRMS) and coping strategies (Brief cope sub-scales).

These hypotheses are based upon the broader literature on coping strategies typically used among individuals with MS and their QoL. The results of such studies indicate that individuals with MS use coping strategies such as task-orientation and a positive attitude less often (McCabe & McKern, 2002). Research also indicates a tendency among individuals with MS to use coping strategies such as venting, humour, isolation, positive comparison, selective attention, and minimization to cope with MS (Farran et al., 2016; Goretti et al., 2010, Kar et al., 2017; McCabe et al., 2004; Montel & Bungener, 2007; Tan-Kristanto & Kiropoulos, 2015). With regards to QoL, literature suggests that individuals with MS report a lower QoL in comparison to the general population. Furthermore, factors such as disease course, social support, employment, and coping strategies have been found to influence the QoL levels among individuals with MS (Janardhan & Bakshi, 2002; Kes et al., 2013; McCabe & McKern, 2002).

4.4. Research design

In this study I made use of a cross-sectional quantitative research design. Data collection was done online from a group of South African people with MS, using a survey comprising of a biographical questionnaire and two self-report instruments.

4.5. Procedure

For this study, data were collected in the following manner. Before starting with data collection, Ms. Non Smit was contacted. Ms. Smit is the Director of the Multiple Sclerosis Society in the Western Cape (MSSSA WC) and has over 30 years of experience with regards to MS. In her capacity as director, Ms. Smit has access to and manages a database of approximately

3000 MS patients geographically dispersed throughout SA. Further, Ms Smit is the founder of an online Facebook support group for persons with MS which now has more than 600 members. This Facebook group is a private group where people with similar challenges can speak and share openly. This support group aims to provide support for individuals diagnosed with MS, their caregivers, families and loved ones and provide information on MS to any person or group of persons with an interest in the disease. This group also creates awareness of MS and the debilitating effect it has on individuals diagnosed with it, specifically in the context of South Africa. Ms Smit was contacted with regards to her help in bridging the gap between the researcher and the participants on the Facebook support group. This decision was made based on the participants' familiarity with her and her knowledge on MS in South Africa.

Ms. Smit provided permission to access the group in order to be able to recruit participants for this study (see Appendix A). After permission was obtained, Ms. Smit posted information (in the form of an advertisement) about this study to the Facebook support group on a weekly basis between 1 August 2018 and 30 October 2018 and members of the group were invited to participate in this study (see Appendix B for invitation). Convenience sampling was therefore used to recruit participants as they were invited to take part in the study on an online Facebook group support group for South African people with MS. The only inclusion criteria for this study was that participants had to be older than 18 years and have a diagnosis of MS made by a health professional. These criteria were set with the aim to incorporate as many participants as possible.

The individuals who decided to participate in this study were able to follow a link (posted on the advertisement) that took them to a page where they were required to give informed consent after reading the informed consent form (see Appendix C for a copy of the informed consent form). After providing informed consent, participants were directed to a biographical questionnaire and two other questionnaires (this will be discussed in section 4.6) to complete.

The types of questions included in the survey is discussed in section 4.6. An online survey comprising of a biographical questionnaire and two self-report instruments were used to collect data concerning QoL and coping strategies utilised. The survey was produced and distributed using the platform, SUNsurveys, a Stellenbosch University electronic survey system. Descriptive texts describing what the questions entail were added to questions where required, to enhance understanding. No time limit was set, given that participants were able to complete the surveys in their own time.

Data collection was projected to take place between 1 August 2018 and 1 September 2018. Since the required number of participants was not reached by 1 September 2018, data collection was extended to 30 October 2018. A total of 616 participants from the Multiple Sclerosis South Africa Western Cape's online Facebook support group attempted the survey. However, the final sample included was 200 because 416 cases had to be removed before the analysis because these data were incomplete.

With regards to the determining the appropriate sample size for this study, I used Green's (1991) formula and a G*Power calculation (Faul, Erdfelder, Lang, & Buchner, 2007; Faul, Erdfelder, Lang, & Buchner, 2009) to estimate the minimum sample size I would need to conduct a multiple regression analysis. Green (1991) states that the formula, N >= 104 + k (where k is the number of predictors you have in your analysis) can be used to determine the appropriate sample size when conducting a multiple regression analysis. According to this formula, the sample size needed to perform a multiple regression analysis in this study is 129 (N >= 104 + 25). Moreover, through using a G*Power calculation (Faul et al., 2007; Faul et al.,

2009) it was determined that the required sample size for a multiple regression analysis in this study was 48. The projected sample size for this study was therefore between 48 and 129. The sample size of this study (*n* = 200) is therefore sufficient for the analysis since my previous calculation showed that I needed between 48 and 129 participants (Faul et al., 2007; Faul et al., 2009; Green, 1991). Furthermore, the participants in this study (members of the Multiple Sclerosis South Africa Western Cape's online Facebook support group) come from many different demographic and socio-economic backgrounds from all over South Africa, which resulted in a diverse sample of participants.

4.6. Data collection measures

4.6.1. Biographical questionnaire

A self-developed biographical questionnaire (see Appendix D) was used to obtain the data essential for descriptive purposes and to provide demographic and clinical (MS sub-type, disease duration) information pertaining to the same of people with MS in this study. Participants' responses were generally limited to those itemized on multiple-choice selections. Examples of the questions that were included are "What is your age?", "What is your gender?", "What is your current employment status?" and "Approximately how many years since you have been diagnosed with multiple sclerosis?".

4.6.2. Coping strategies.

Coping strategies were measured with the use of the Brief Cope questionnaire (see Appendix E for a copy of this questionnaire). The Brief Cope is based on the original version of the COPE questionnaire. The COPE questionnaire was developed by Carver, Scheier and Weintraub (1989) to assess the different ways in which people respond to stress (Lyne & Roger, 2000). The COPE questionnaire is made up of 53-items and comprises of five scales (with four items each) that measure active coping, planning, suppression of competing activities, restraint coping, seeking of instrumental social support, social support, positive reinterpretation, acceptance, denial, voicing of emotions/venting, behavioural detachment, and mental detachment (Carver, Scheier & Weintraub, 1989).

In order for a shorter version of the original COPE to be used, the Brief Cope was developed. The Brief Cope was developed to measure the coping strategies used amongst adults with any type of disease (Carver, 1997; Yusoff, Low, & Yip, 2010). The Brief Cope is based on the same theoretical models (the model on behavioural self-regulation and Lazarus's model on stress) as the original COPE questionnaire (Bose, Bjorling, Elfstrom, Persson, & Saboonchi, 2015). The Brief Cope has 28 items as it is made up of 14 sub-scales, which respectively contain two items per sub-scale. The sub-scales comprise of "self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion and self-blame" (Yusoff et al., 2010, p. 41).

The responses on the scale range from 1 (I have not been doing this at all) to 4 (I've been doing this a lot). There is no overall score for this scale. The scores for the Brief Cope are calculated based on the different sub-scales. In his research, Carver (1997) mention that researchers should use the Brief Cope as adaptably as they find appropriate. With this being said, and since there is no overall score for the scale, a higher score on any sub-scale indicates more reliance on that type of coping strategy (Carver, 1997; Hastings et al., 2005).

Studies have shown that the internal consistency of the Brief Cope ranges from 0.6 to 0.79, which according to George and Mallery (2003) is an acceptable reliability score (Cooper, Katona, and Livingston 2008; Somer et al., 2010; Yusoff et al., 2010). South African studies using the Brief Cope scale as a measure also reported that the scale is a reliable measure, although reliability varies somewhat across the various studies (Louw & Viviers, 2010; Makin, Forsyth, Visser, Sikkema, Neufeld, & Jeffery, 2008; Mostert & Joubert, 2005). For example, the study by Mostert and Joubert (2005) utilised the Brief Cope scale to measure coping among South African police officers. Their results indicated that the Brief Cope displayed reliability indices ranging between 0.83 and 0.92 (Mostert & Joubert, 2005). Similar results were obtained by Makin et al. (2008) who researched factors affecting disclosure in South African HIV-positive pregnant women. Their results indicated a reliability coefficient of .63, which is acceptable (Makin et al., 2008; George & Mallery, 2003).

Concerning the validity, a study by Yusoff et al. (2010) among thirty-seven Malaysian women with breast cancer undergoing treatment of adjuvant chemotherapy measured the discriminant validity of the Brief Cope scale. The authors of this study ascertained that the Brief Cope is a valid instrument among the sample -who are from a low and middle-income country (LMIC) - due to its ability to detect changes (indicated by the mean differences and the effect size values). South Africa is also a LMIC which suggests that the results from this study could be comparable to South Africa. However, I could not find any study in South Africa that specifically report on the validity of the Brief Cope. Furthermore, a longitudinal study by Cooper, Katona and Livingston (2008) of 125 individuals with Alzheimer’s disease and their carers from London and the South-East Region of England, tested the content validity of 3 composite scales (problem-focussed, emotion-focussed, dysfunctional coping) of the Brief Cope. Similarly, the authors of this study found that the Brief Cope (using the composite scales) was a valid instrument among their sample (Cooper et al., 2008).

4.6.3. Quality of Life (QoL).

In this study, QoL was evaluated by using the Multiple Sclerosis International Quality of Life questionnaire (MusiQoL) (See Appendix F for a copy of this questionnaire, and Appendix G for the user agreement). The MusiQoL is an international, multi-dimensional, self-administered questionnaire produced specifically to assess the QoL of individuals with MS, and is available in 14 languages (Simeoni et al., 2008). The MusiQoL is made up of 31 items and designates the following dimensions "activity of daily living (ADL), psychological well-being (PWB), relationships with friends (RFr), symptoms (SPT), relationships with family (RFa), relationship with the healthcare system (RHCS), sentimental and sexual life (SSL), coping (COP), and rejection (REJ)" (Fernández, Baumstarck-Barrau, Simeoni, Auquier, & MusiQoL Study Group, 2011, p. 1239). For the use of the MusiQoL in this study, the dimension labelled 'coping' was omitted. This was done with the intention of not having two different measures (MusiQoL coping dimension and Brief Cope) that assess coping.

The responses on this questionnaire range from Never/Not at all to Always/Very much. A global index score can be calculated by determining the average of the separate dimension scores (which ranges from 0 to 100) with scores closer to 100 representing an enhanced QoL. According to Simeoni et al. (2008) a sample in which the MusiQoL questionnaire is used can be categorized into two, using the scores of the validation population -form the study by Simeoni et al. (2008) - as norms. For example, low QoL scores can be attributed to individuals reporting a score under or the median (Med= 63.83) and high QoL scores for individuals reporting a score over the median (Simeoni et al., 2008).

A study by Simeoni et al. (2008) using the information of patients recruited from 15 different countries (Argentina, Canada, France, Germany, Greece, Israel, Italy, Lebanon, Norway, Russia, South Africa, Spain, Turkey, UK and USA) ascertained that the internal consistency (indicated by Cronbach's alpha reliabilities) ranged from 0.68 to 0.92, which as stated by George and Mallery (2003) is an acceptable reliability coefficient.

Validity (external and construct validity) was established through the same study by Simeoni et al. (2008; p. 222). This study was conducted with 1992 patients who were diagnosed with MS from the following countries "Argentina (*n* = 27), Canada (*n* = 77), France (*n* = 179), Germany (*n* = 209), Greece (*n* = 92), Israel (*n* = 66), Italy (*n* = 379), Lebanon (*n* = 20), Norway (*n* = 104), Russia (*n* = 201), South Africa (*n* = 53), Spain (*n* = 224), Turkey (*n* = 228), UK (*n* = 36) and USA (*n* = 97)" (Simeoni et al., 2008; p. 222). With regards to external validity, the authors reported that the dimension scores of the MusiQoL correlated significantly with all Short Form 36 (SF-36) scores. In exploring the construct validity of the MusiQoL, the discriminant validity was determined by dimension mean scores across patient groups that were expected to differ in their socio-demographic (e.g., age and gender) or clinical features (e.g., clinical status, EDSS status and duration of MS). The results demonstrated discriminant validity by gender, socio-economic and health status. The MusiQoL is therefore a reliable and valid international scale to evaluate QoL in patients with MS (Simeoni et al., 2008).

4.7. Data analysis

The data were analysed using Statistical Package for the Social Sciences (SPSS) software version 25, and a 5% significance level ($p < .05$) was used as a guideline for significant results. Firstly, descriptive statistics were calculated for the demographic variables. Categorical variables (such as gender and income) were represented using frequency tables. Furthermore, continuous variables (such as age) were reported through means (M) and standard deviations

(SDs). Cronbach's alpha coefficients of the MusiQoL and Brief Cope was calculated to determine reliability of the measurement scales prior to proceeding with inferential statistics.

The first research question regarding the relationship between coping strategies and QoL was dealt with by performing correlation analyses (Pearson's r). This was done to explore the relationship between QoL total score (global index score) and coping (14 sub-scales of coping on the Brief Cope).

The second research question, which was concerned with whether males and females differ in terms of coping strategies used, and if this difference was significant, was addressed by running independent sample t-tests.

The third research question, that was concerned whether MS sub-types (RRMS, PPMS, SPMS, and PRMS) differ in terms of coping strategies used, and if this difference was significant, was addressed by performing one-way ANOVA's.

The fourth research question, which was concerned with whether males and females differ in terms of overall QoL score, and if this difference was significant, was similarly addressed by running independent sample t-tests.

The fifth research question – which was concerned with whether MS sub-types (RRMS, PPMS, SPMS, and PRMS) differ in terms of overall QoL score, and if this difference was significant- was addressed by running one-way ANOVA's.

The last research question was approached by performing a hierarchical multiple regression. This was used to explore whether biographical factors (such as gender, age, employment, relationship status), clinical factors (MS sub-type), and coping strategies (Brief cope sub-scales) have a significant influence on the QoL of individuals with MS.

Before performing the multiple regression analysis, multiple regression diagnostics were explored. These include: determining whether the sample size was sufficient, identifying outliers in the data, determining multicollinearity (high correlations between the independent variables), linearity (a linear relationship between the outcome variable and the independent variables), and homoscedasticity (the error variance should be the same across all values of the independent variables). Following this exploration, the sample size was sufficient (195 participants), there were no obvious outliers, multicollinearity figures were below the cut-off point (Variance Inflation Factor [VIF] <10), the sample was normally distributed (as determined by the Shapiro-Wilk test and normality plots) and residuals were mostly equally distributed (the error variance was the same for all values of the independent variables). Since none of the assumptions were violated, the multiple regression analysis was run.

4.8. Ethical considerations and ethical approval

Before starting with data collection, I went through an ethics approval process at Stellenbosch University. This involved submission of a research proposal to the Departmental Ethics Screening Committee (DESC). Departmental clearance was obtained on 17 May 2018, thereafter the proposal was submitted to the Health Research Ethics Committee (HREC). No data were collected before receiving ethical clearance from the HREC. Ethical approval was received from the HREC (Project ID: 6716) on 31 July 2018 (see Appendix H for the ethical approval letter). Additionally, this study was considered as a low-risk study, because the probability and magnitude of harm or discomfort anticipated in the research, is not greater, in and of itself, than that ordinarily encountered in daily life, or during the performance of routine psychological examinations or tests. When ethical clearance was obtained from the HREC on 31 July 2018 data collection began on 1 August 2018. Before starting the survey, the purpose of the research was electronically explained to the participants and informed consent was obtained as participants had to approve that they understood the information distributed to them and that they were taking part on a voluntary basis. At any time, the participants were able to choose that they do not want to take part in the study any longer and withdraw without any adverse consequences. To protect the participants' anonymity and confidentiality, all questionnaires were completed anonymously, therefore ensuring that no identifying information was collected. To further guarantee privacy, the data set was saved on a computer that was protected with a password, which only my supervisors (Dr Chrisma Pretorius (supervisor) and Dr Bronwynè Coetzee (co-supervisor) and I have access to. Similarly, after the study has been completed, the data will be stored safely for 5 years after which it will be discarded appropriately.

4.9. Conclusion

In this chapter I discussed the research methodology and design used in this quantitative study. In addition, I defined the primary aim, research questions, and hypotheses of this study. I also discussed the procedures, recruitment of participants, data collection measures data analysis, and ethical considerations. I will outline and discuss the results of this study in the subsequent chapter.

Chapter 5

Results

5.1. Introduction

In this chapter, I present the results of the data analyses performed on the data set. To begin with, I present the biographical characteristics of the sample of participants who took part in this study. Thereafter, I present the results of the reliability analyses performed on the measures used in this study, namely the Brief Cope and the MusiQoL questionnaire. I then report on the findings of the relationship between QoL and coping. Thereafter, the results of the independent sample t-tests and ANOVA's are reported. These findings demonstrate the differences in the mean coping and QoL scores among males and females with MS and the different sub-types of MS (RRMS, PPMS, SPMS, and PRMS). I conclude this chapter with the results of the hierarchical multiple regression analysis, which explored the predictors of QoL in this sample.

5.2. Biographical and clinical characteristics of the sample

A total of 616 participants from the Multiple Sclerosis South Africa Western Cape's online Facebook support group attempted the survey. The final sample from which data was obtained consisted of 200 participants. Participants that were excluded from the study (n=416) did not complete the survey in full. The only inclusion criteria for this study was that participants had to be older than 18 years and have a diagnosis of MS made by a healthcare professional (neurologist). The biographical characteristics of this MS sample is displayed in Table 5.1

Table 5.1

Biographical characteristics of the sample

		n	(%)	M	SD
Age (years)				43.74	11.19
Gender	Male	31	15.5		
	Female	169	84.5		
Relationship status	Single (never married)	47	23.5		
	Married	128	64		
	Widowed	5	2.5		
	Divorced/separated	20	10		
Employment Status	Employed full time	73	36.5		
	Employed part time	27	13.5		
	Unemployed (seeking work)	11	5.5		
	Unemployed (not seeking work)	9	4.5		
	Student	2	1		
	Retired	14	7		
	Homemaker	13	6.5		
	Self-employed	26	13		
	Unable to work	25	12.5		

Note. M = mean, SD = Standard Deviation

As can be seen in Table 5.1 the mean age for the sample was 43.74 years (range: 22-73 years). The majority of the sample was female (85.6%). Furthermore, the majority (63%) of the sample reported that they are married and employed full time (37.5%). The clinical characteristics of the participants are reported in Table 5.2.

Table 5.2

Clinical characteristics of the sample

		n	(%)
Diagnosed with MS	Yes	200	100
	No	0	0
Time since diagnosis	Less than a year	16	8
	1-5 years	63	31.5
	5-10 years	50	25
	More than 10 years	71	35.5
Type of MS	Relapsing/remitting MS (RRMS)	146	73
	Primary progressive MS (PPMS)	11	5.5
	Secondary progressive MS (SPMS)	11	5.5
	Progressive relapsing MS (PRMS)	11	5.5
	I am not sure	21	10.5

Note. n = sample size

As can be seen in Table 5.2, all 200 participants confirmed that their diagnosis was made by a healthcare professional (neurologist) and were therefore included in the study. A sizeable proportion of the sample (35.5 %) had been diagnosed for more than 10 years. Further, the majority (73 %) of the sample reported a diagnosis of relapsing/remitting MS (RRMS).

5.3. Reliability of data collection materials

5.3.1. Brief Cope questionnaire

Reliability analysis was conducted on the Brief Cope by calculating Cronbach's alphas for each of the 14 sub-scales. A common practice regarding Cronbach's alpha coefficient sizes is that a score of <.6 is poor, a score between .6 and < .7 is moderate, scores ranging from .7 to <.8 is good, scores between .8 to <.9 is very good, while scores more than .9 is regarded as an excellent size (Hair, Celsi, Money, Samuoel, & Page, 2011). The Brief Cope demonstrated an overall reliability of .73 (M=69.73, SD=10.33) which is regarded as good (Hair et al., 2011). The results of the reliability analyses performed on the Brief Cope sub-scales are displayed in Table 5.3. As seen in Table 5.3, the Brief Cope sub-scale reliabilities ranged from .50 (poor) for the mental disengagement sub-scale to .94 (excellent) for the substance use sub-scale. The subscales that indicated poor reliability (<.6) was venting and mental disengagement.

Table 5.3

Reliability analysis of Brief Cope sub-scale

Instrument	M	SD	α
Planning	5.80	1.85	.73
Active coping	6.25	1.74	.64
Instrumental support	4.93	1.76	.69
Emotional support	5.65	1.87	.79
Venting	4.69	1.72	.52

Positive reframing	5.74	2.00	.77
Acceptance	6.67	1.72	.77
Humour	5.01	2.14	.85
Religion	5.10	2.36	.87
Behavioural disengagement	3.27	1.66	.64
Mental disengagement	5.64	1.82	.50
Denial	3.50	1.96	.83
Substance use	3.13	1.82	.94
Self-blame	4.39	2.05	.72

Note. M=Mean, SD= Standard Deviation, α= Cronbach's alpha coefficient

5.3.2. Multiple Sclerosis International Quality of Life questionnaire

The MusiQoL questionnaire demonstrated very good internal consistency with a Cronbach's alpha of .80 (M=54.73, SD=28.52). The results of the reliability analyses performed on the nine sub-scales of the MusiQoL questionnaire is displayed in Table 5.4. As seen in Table 5.4 the internal consistency for the nine sub-scales of the MusiQoL questionnaire ranged from .74 (good) to .92 (excellent) which are acceptable reliability scores as maintained by Hair et al. (2011). It is important to note that the sub-scale 'coping' was removed, as to not have two dimensions that measure coping (i.e. Brief Coping and MusiQoL coping sub-scale). After removing the sub-scale 'coping', The MusiQoL questionnaire demonstrated good internal consistency with a Cronbach's alpha of .75 (M=54.48, SD=23.68).

Table 5.4

Reliability analysis of the MusiQoL questionnaire sub-scales

Instrument	M	SD	α
Activities of daily living	23.15	7.82	.92
Psychological wellbeing	11.84	3.93	.87
Symptoms	11.81	3.48	.74
Relationships with friends	8.88	2.83	.76
Relationships with family	10.54	3.34	.87
Sentimental and sexual life	5.92	2.89	.83
Coping	6.68	2.55	.86
Rejection	8.01	2.10	.88
Relationship with healthcare system	11.01	3.47	.92

Note. M=Mean, SD= Standard Deviation, α= Cronbach’s alpha coefficient

5.4. Relationship between coping and QoL (Correlation analysis)

The first objective of this study was to determine whether a relationship exists between coping strategies used by individuals with MS and their QoL. In line with this objective, I hypothesised that a relationship will exist between the coping strategies used by individuals with MS and their levels of QoL. More specifically, I hypothesised that individuals who use coping strategies such as planning, active coping, emotional support, and positive reframing will report high levels of QoL (global index score > 63.83).

A correlation analysis was conducted to investigate the relationship between coping strategies and QoL (global index score) using Pearson's r. Regarding the interpretation of effect size values, Cohen (1988) suggests that the effect size is low if the value of *r* varies around .1, medium if *r* varies around .3, and large if *r* varies more than .5 As reported in Table 5.5 significant positive correlations were reported among four of the coping sub-scales (emotional support, venting, positive reframing, acceptance) and QoL (global index score), and significant negative correlations were found among five of the coping sub-scales (behavioural disengagement, mental disengagement, denial, substance use, self-blame) and QoL (global index score). No significant correlations were reported among the rest of the Brief Cope sub-scales (planning, active coping, instrumental support, humour, religion) and QoL.

The first significant positive correlation was found between the sub-scale emotional support and QoL, *r* = .24, p<.05. Next, a significant positive correlation was found between venting and QoL, *r* = .30, p<.05. The third significant positive correlation was reported between positive reframing and QoL, *r* = .26, p<.05. Lastly, a significant positive correlation *(r* = .43, p<.05) was reported between acceptance and QoL. The effects sizes of the significant positive correlations between QoL and these four coping sub-scales can be interpreted as medium, which indicates a moderate relationship. Furthermore, these positive correlations indicate that individuals in this study who rely on emotional support, venting, positive reframing, and acceptance as coping strategies have significantly higher QoL scores (global index score).

The significant negative correlations that were found among four of the coping sub-scales and QoL (global index score) were behavioural disengagement (*r* = -.45, p<.05), mental disengagement (*r* = -.26, p<.05), denial (*r* = -.48, p<.05), substance use (*r* = -.31, p<.05), and self-blame (*r* = -.63, p<.05). These negative correlations indicated effect sizes of a medium value, which shows that the relationship between QoL and these variables (behavioural -and mental disengagement, denial, substance use) was moderate. Looking at the significant negative correlation between QoL and self-blame, a large effect size was indicated, which point towards a strong relationship between these variables. Moreover, these findings indicate that QoL is poorer amongst those who rely on the coping sub-scales' behavioural disengagement, mental disengagement, denial, substance use, and self-blame as coping strategies, thus rejecting the first hypothesis. No significant correlations were found among the remaining coping sub-scales (planning, active coping, instrumental support, humour and religion) and QoL. These results are displayed in Table 5.5.

Table 5.5

Correlations between coping strategies and QoL (global index score)

Variables: *Brief cope sub-scales*	M (SD)	Sig (*p*)	Effect Size (*r*)
Planning	5.80 (1.85)	.19	-.09
Active coping	6.25 (1.74)	.59	.04
Instrumental support	4.92 (1.76)	.71	.03
Emotional support	5.65 (1.87)	.00*	.24
Venting	4.69 (1.72)	.00*	.30
Positive reframing	5.74 (2.00)	.00*	.26
Acceptance	6.67 (1.72)	.00*	.43

Humour	5.00 (2.14)	.64	-.10
Religion	5.10 (2.36)	.27	-.08
Behavioural disengagement	3.27 (1.65)	.00*	-.45
Mental Disengagement	5.63 (1.82)	.00*	-.26
Denial	3.49 (1.96)	.00*	-.48
Substance use	3.12 (1.81)	00*	-.31
Self-blame	4.39 (2.05)	00*	-.63

Note. M= mean*;* SD= standard deviation*, r*= Pearson's correlation
*$p < .05$

5.5. Coping strategies and QoL levels amongst South Africans with MS

5.5.1. Coping strategies

The second objective of this study was to determine if males and females differ in terms of coping strategies used, and if this difference was significant. Moreover, the third objective of this study was to determine if MS sub-types (RRMS, PRMS, SPMS, and PPMS) differ in terms of coping strategies used, and if this was difference significant. In line with this objective, I hypothesised that females with MS would score higher on coping strategies such as detachment, seeking social support, and focussing on the positive than males. I also hypothesised that those with SPMS and PRMS MS sub-types would score higher on coping strategies such as behavioural disengagement, mental disengagement, denial, substance use, self-blame, than those with RRMS and PPMS MS sub-types.

The mean of each of the 14 sub-scales was calculated to obtain a coping score for that sub-scale, as there is no overall score for this scale. For instance, the scores obtained on items 14 and 25 were added to arrive at a mean score for the sub-scale planning and items 4 and 11 and were summed to obtain a mean score for the sub-scale substance use.

Through independent sample t-tests, it was established whether males and females differ in terms of coping strategies used, and if this difference is significant. The independent sample t-test was supplemented with an effect size calculation (Cohen's *d*) to determine the importance of the differences between male and female coping scores. Furthermore, to determine if there were differences in the mean coping scores between MS sub-types (RRMS, PPMS, SPMS, and PRMS) a one-way ANOVA (as well as a Post Hoc test on significant results) was conducted, which links to the third hypothesis.

5.5.1.1. Gender differences in coping scores

The results of the independent sample t-test indicated small differences between male and female coping variances, however none of these differences were significant. Therefore, failing to reject the null hypothesis. Regarding the interpretation of effect size values, Cohen (1988) suggest that the effect size is low if the value of Cohen's *d* varies around .1, medium if Cohen's *d* varies around .3, and large if Cohen's *d* varies more than .5 The effect sizes of the respective significant differences were planning with a low effect size (.03), active coping with a medium effect size (.33), positive reframing with a low effect size (.06), and acceptance that reported a medium effect size (.27). The results are reported in Table 5.6.

Table 5.6

Gender differences in coping sub-scale scores (*n = 200*)

Brief Cope Sub-scale	Male score M (SD)	Female score M (SD)	Sig. (*p*)	Effect size (*d*)
Planning	5.74 (2.17)	5.80 (1.79)	.83	.03
Active coping	5.71 (5.70)	6.35 (1.65)	.06	.33
Instrumental support	4.90 (1.71)	4.93 (1.77)	.94	0.1
Emotional support	5.48 (2.01)	5.68 (1.85)	.59	.10
Venting	4.93 (1.95)	4.64 (1.67)	.38	.16
Positive reframing	5.61 (2.39)	5.76 (1.93)	.70	.06
Acceptance	6.22 (2.16)	6.75 (1.62)	.11	.27
Humour	5.12 (2.40)	4.98 (2.09)	.72	.06
Religion	5.16 (2.66)	5.08 (2.31)	.87	.03
Behavioural disengagement	3.19 (1.60)	3.28 (1.66)	.78	.05
Mental disengagement	5.54 (1.84)	5.56 (1.82)	.77	.06
Denial	3.83 (2.22)	3.43 (1.90)	.28	.19
Substance use	3.51 (2.04)	3.05 (1.77)	.19	.24
Self-blame	4.48 (1.98)	4.36 (2.06)	.77	.05

Note. M = mean; SD= standard deviation

**p* <. 05

5.5.1.2. Influence of MS sub-type on coping

Of the 200 participants, 21 were unsure of their diagnoses and were therefore excluded from this particular analysis. The analysis was therefore run on 179 participants. A Tukey post hoc test (Tukey HSD test) was run on the significant result obtained from the one-way ANOVA for the purpose of confirming where the differences occurred between groups. Effect sizes (using eta-squared/η^2) were also calculated.

The results of the one-way ANOVA specified one significant difference between MS sub-types and the coping sub-scale denial, $F(4,195) = 3.22$, $p<.05$. Post hoc comparisons using the Tukey HSD test indicated that the mean coping score difference between RRMS (M= 3.27, SD= 1.77) and PPMS (M=5.18, SD=2.75) on the sub-scale denial was significant. No other significant differences were indicated between the coping sub-scale denial and the other MS sub-types (PRMS and SPMS). This significant difference indicates that individuals diagnosed with PPMS rely on denial as a manner of coping more than the individuals diagnosed with RRMS, which is a less severe MS sub-type. Taken together, these results indicate that MS sub-type has an influence on the coping strategies utilised by individuals diagnosed with MS. Specifically, these results suggest that when an individual is diagnosed with PPMS, they are more likely to rely on denial as a coping strategy than those diagnosed with RRMS.

When assessing the effect size of a one-way ANOVA analysis (using eta-squared/η^2) a rule of thumb is that $\eta^2 = 0.01$ indicates a small effect, $\eta2 = 0.06$ indicates a medium effect, and $\eta^2 = 0.14$ indicates a large effect size (Cohen, 1988). The effect size of the significant difference was .06, which is regarded as a medium effect. This effect size indicates that 6.20% of the variance between the MS sub-types can be explained by the coping sub-scale, denial. The results of this analysis are presented in Table 5.7.

Table 5.7

Coping strategies used by MS sub-types (n = 179)

Coping strategies	RRMS M (SD) *n*= 146	PPMS M (SD) *n*=11	SPMS M (SD) *n*=11	PRMS M (SD) *n*=11	Sig. (*p*)	Effect size (η^2)
Planning	5.70 (1.88)	6.36 (1.96)	6.18 (1.88)	6.54 (1.57)	.40	.01
Active coping	6.20 (1.74)	5.81 (2.22)	6.27 (1.90)	6.91 (1.22)	.63	.01
Instrumental support	4.88 (1.74)	5.27 (1.67)	5.18 (1.77)	5.00 (1.67)	.94	.00
Emotional support	5.78 (1.86)	6.00 (1.48)	5.45 (1.57)	5.01 (2.02)	.23	.02
Venting	4.71 (1.66)	4.91 (1.81)	4.63 (2.01)	4.73 (1.42)	.97	.00
Positive reframing	5.82 (1.95)	5.73 (2.64)	5.54 (1.86)	5.63 (1.42)	.91	.00
Acceptance	6.75 (1.63)	6.09 (2.21)	6.72 (1.79)	6.54 (1.75)	.73	.01
Humour	4.97 (2.10)	5.18 (2.48)	4.54 (1.81)	5.45 (2.11)	.86	.01
Religion	4.83 (2.33)	5.81 (2.40)	5.09 (2.38)	6.09 (2.30)	.08	.04
Behavioural disengagement	3.17 (1.60)	3.00 (1.48)	4.27 (1.84)	3.81 (1.66)	.19	.03
Mental Disengagement	5.62 (1.82)	4.90 (1.70)	6.36 (1.69)	5.18 (2.04)	.20	.03
Denial	3.26 (1.77)	5.18 (2.75)	3.36 (1.80)	4.00 (2.09)	.01*	.06
Substance use	3.06 (1.79)	3.55 (2.42)	4.09 (2.58)	2.90 (1.13)	.37	.02
Self-blame	4.31 (1.97)	5.09 (2.46)	5.09 (2.66)	4.54 (1.57)	.49	.01

Note. M = mean; SD= standard deviation; *p*= significance; η^2= effect size

*$p < .05$

5.5.2. Quality of life

The fourth objective of this study was to ascertain whether males and females differ in terms of overall QoL score, and if this difference is significant. Furthermore, the fifth objective of this study was to establish if MS sub-types (RRMS, PPMS, SPMS, PRMS) differ in terms of overall QoL score, and whether this difference is significant. In line with these objectives, it was hypothesised that females with MS would report higher QoL levels than males and that individuals with SPMS and PRMS MS sub-types would report lower levels of QoL (global index score <63.83) than those with RRMS and PPMS MS sub-types as reported in MS research (Janardhan & Bakshi, 2002; Kes et al., 2013; McCabe & McKern, 2002).

The decision was made to remove the coping dimension from the MusiQoL, as to not have two dimensions that measure coping (Brief Cope and MusiQoL). Before scoring the MusiQoL the negatively worded item scores were reversed so that higher scores indicated higher level of QoL. Dimension scores were obtained by computing the mean of the item scores of the dimension and were linearly transformed on a 0–100 scale. A global index score was calculated through the average of the separate dimension scores, which ranges from 0 to 100, with scores closer to 100 representing a better QoL. Of the 200 participants in this sample, 4 did not answer the questions of the MusiQoL (used to determine QoL) fully. These cases were therefore excluded from the following analyses.

The mean global index score obtained from this sample was 51.33 (SD=21.61), with a minimum score of 1.36 and maximum score of 100 being reported. These findings- regarding QoL scores amongst individuals with MS- are similar to what is reported in research on MS and QoL (Farran et al., 2016; Kes et al., 2013; Motl et al., 2013; Papuć & Stelmasiak, 2012), and is in line with the last hypothesis of this study. Therefore, failing to reject the hypothesis. The mean scores of the eight QoL domains further indicated that this sample scored the rejection domain (M=73.63) the highest. Participants scored the sentimental and sexual life domain (M=43.97) the lowest, followed by activities of daily living (M=47.23), relationships with friends (M=47.67), psychological wellbeing (M=47.75), and symptoms (M=48.97). These results are similar to those of related studies in which it was indicated that individuals with MS report difficulty with regards to their social support, symptoms, psychological wellbeing, and physical capabilities (Hopman et al., 2006; Montel & Bungener, 2006; Patti et al., 2007). The mean scores and standard deviations of the dimensions of the MusiQoL are reported in Table 5.8.

Table 5.8

Mean scores of Multiple Sclerosis International Quality of Life questionnaire sub-scales (n=196)

Sub-scales	M	SD
Activities of daily living	47.23	24.06
Psychological wellbeing	47.75	25.69
Symptoms	48.97	22.07
Relationships with friends	47.67	23.57
Relationships with family	62.58	27.28
Sentimental and sexual life	43.97	32.06
Rejection	73.63	27.87
Relationship with healthcare system	64.73	28.53

Global index score	51.33	21.61

Note. n= number of participants, M=mean, SD= standard deviation

5.5.2.1. Gender differences in QoL scores

To ascertain whether there were significant differences in terms of overall QoL score between males and females, independent sample t-tests were utilised. The independent sample t-test were supplemented with an effect size calculation (using Cohen's *d*) to determine the importance of the differences between male and female QoL scores. It was found that there are small differences in the QoL scores of male (M=50.20, SD=19.25) and female (M=51.54, SD=22.06) participants in this sample. This difference was however not significant. Therefore failing to reject the null hypothesis. No significant differences were found between gender and the MusiQoL sub-scales. The results from this analysis are shown in Table 5.9.

Table 5.9

Gender differences within the sub-scales of the MusiQoL (n = 200)

MusiQoL sub-scales	Male QoL score M(SD)	Female QoL score M (SD)	Sig (*p*)	Effect size (*d*)
Activities of daily living	48.28 (22.06)	47.03 (24.46)	.28	.05
Psychological wellbeing	44.96 (29.77)	48.26 (24.94)	.18	.12
Symptoms	56.05 (20.63)	47.67 (22.13)	.40	.44
Relationships with friends	45.70 (23.56)	48.02 (23.62)	.99	.09
Relationships with family	61.29 (24.68)	62.82 (27.79)	.28	.05

Sentimental and sexual life	44.76 (25.77)	43.83 (33.16)	.76	.03
Rejection	69.76 (28.64)	74.33 (27.76)	.86	.16
Relationship with healthcare system	56.45 (31.00)	66.24 (27.88)	.20	.33
Global index score	50.20 (19.25)	51.54 (22.06)	.30	.06

Note. M=mean; SD= standard deviation; *p*= significance; *d*= effect size

* $p < .05$

5.5.2.2. Influence of MS-sub-type on QoL scores

The mean QoL scores (obtained through the MusiQoL questionnaire) of the four MS sub-types were as follows: RRMS (M =54.66), PPMS (M =33.30), SPMS (M =37.75), and PRMS (M= 44.55). From these results it is evident that participants from this sample diagnosed with the MS sub-type, RRMS, scored significantly higher on the QoL measure in comparison to the other MS sub-types. This higher score indicates that individuals with MS with the RRMS sub-type self-report a higher level of QoL, compared to those with other MS types (PPMS, SPMS, and PRMS).

To determine whether MS sub-types significantly differ in terms of overall QoL score, one-way ANOVA's were used. A Tukey post hoc test (Tukey HSD test) was run along with the significant result obtained from the one-way ANOVA, for the purpose of confirming where the differences occurred between groups. Effect sizes (using eta-squared/η^2) were also calculated.

Significant differences were found between MS sub-types and activities of daily living ($F(4,195) = 11.47$, $p<.05$), symptoms ($F(4,195) = 3.01$, $p<.05$), rejection ($F(4,195) = 8.45$, $p<.05$), as well as the mean QoL score/global index score ($F(4,195) = 4.46$, $p<.05$). These differences indicate that the type of MS that individuals in this sample are diagnosed with have an influence on their daily activities, symptoms, how they experience rejection as well as their overall QoL. Again, the rule of thumb regarding the effect size of a one-way ANOVA's results was used where $\eta^2 = 0.01$ indicates a small effect, $\eta^2 = 0.06$ indicates a medium effect, and $\eta^2 = 0.14$ indicates a large effect (Cohen, 1988). The effect size of the significant differences between MS sub-types and QoL were activities of daily living ($\eta^2 = .19$) with a large effect size, symptoms ($\eta^2 = .05$) with a medium effect size, rejection ($\eta^2 = .04$) with a medium effect size and global index score ($\eta^2 = .09$) with a medium effect size.

Post hoc comparisons using the Tukey HSD test indicated significant differences regarding the activities of daily living score between the MS sub-types RRMS (M=52.58 SD= 21.86) and PPMS (M= 25.28 SD=13.65), RRMS (M=52.58 SD = 21.86) and SPMS (M=17.89 SD=15.94), as well as RRMS (M=52.58 SD = 21.86) and PRMS (M= 30.96 SD=21.67). These results indicate that the mean score from the sub-scale activities of daily living, were higher among the MS sub-type RRMS and that this area of QoL is therefore of a higher quality in comparison to the other MS sub-types.

Significant differences regarding the mean scores of the MusiQoL subscale, symptoms, were also reported between RRMS (M=51.02 SD=21.29) and PRMS (M=31.25 SD=15.56). Again, this result indicates that the symptoms, and their effect, are less troubling among those diagnosed with RRMS in comparison to those diagnosed with PRMS, which is a more severe type of MS. Next, significant differences in the mean rejection scores between RRMS (M= 79.19 SD=24.22) and PPMS (M=40.90 SD=26.86) were also reported. This result shows that rejection is experienced less among individuals diagnosed with RRMS and more among those diagnosed with PPMS, which is a more severe type of MS. Lastly, significant differences between the mean

QoL/global index score were found amid RRMS (M=54.65 SD=20.07) and PPMS (M=33.30 SD=19.03). This difference shows that the QoL is better among individuals diagnosed with RRMS (which is the least severe type of MS) than the other more severe, sub-types (PPMS, SPMS, PRMS).

Taken together these results outline that the MS sub-type has an effect on the QoL of diagnosed individuals. Moreover, the differing severity of the MS diagnosis – ranging from RRMS, PPMS, SPMS, and PRMS- also plays a role in the QoL of individuals diagnosed. Similar to what is reported in MS research (Chiaravalloti & DeLuca, 2008; Cross et al., 2011), these results indicate that the QoL (as well as activities of daily living, symptoms, and rejection) is better among individuals diagnosed with RRMS, which is the least severe MS sub-type. The results of the one-way ANOVA are displayed in Table 5.10.

Table 5.10

Significance of one-way ANOVA of the MS sub-types (n = 179)

MusiQoL sub-scales	RRMS M (SD) *n*= 146	PPMS M (SD) *n*=11	SPMS M (SD) *n*=11	PRMS M (SD) *n*=11	Sig. (*p*)	Effect size (η^2)
Activities of daily living	52.59 (21.86)	25.29 (13.65)	17.90 (15.94)	30.97 (21.67)	.00*	.19
Psychological wellbeing	49.70 (25.60)	31.25 (26.36)	43.75 (26.22)	43.75 (26.07)	.21	.02
Relationships with friends	48.23 (23.41)	46.21 (23.97)	52.27 (20.44)	42.42 (23.40)	.84	.00
Symptoms	54.54 (21.29)	42.61 (24.17)	39.77 (24.57)	31.25 (15.56)	.02*	.05
Relationships with family	63.41 (27.42)	64.39 (24.17)	54.54 (23.38)	64.39 (28.40)	.76	.00

Relationship with healthcare system	68.12 (27.55)	48.49 (27.08)	60.61 (21.76)	62.12 (34.23)	.05	.04
Sentimental and sexual life	44.66 (32.58)	32.95 (25.17)	26.14 (30.85)	48.86 (27.07)	.17	.03
Rejection	79.02 (24.22)	40.91 (26.86)	56.82 (37.65)	56.82 (30.29)	.00*	.15
Global Index score	54.66 (20.07)	33.30 (19.04)	37.75 (25.99)	44.55 (21.02)	.00*	.09

Note. M=mean; SD= standard deviation; *p*= significance; η^2= effect size

* $p < .05$

5.6. Hierarchical Multiple regression analysis

5.6.1. Assumptions of regression and regression diagnostics

Of the 200 participants in this sample, 5 did not answer the questions of the MusiQoL (used to determine QoL levels) fully. These cases were deleted list wise for the regression analysis. The regression analysis was therefore performed on a total of 195 participants.

Before performing the regression analysis, the data were checked for normality (by looking at the skewness and kurtosis, the Shapiro Wilk test, and the plots-histogram and Q-Q plots). Regarding skewness and kurtosis, the data ranged between -1.96 and +1.96. These data were therefore regarded as normal. All of the p-values resulting from the Shapiro-Wilk test were above 0.05, indicating normality. Finally, the normality plots visually indicated that the data were normally distributed.

Furthermore, the multiple regression diagnostics (sample size, outliers, multicollinearity, linearity, and homoscedasticity) were also tested. Following the tests, the sample size was sufficient, there were no major outliers, multicollinearity figures were below the cut-off point, the sample was normally distributed, and residuals were mostly equally distributed. None of the assumptions were violated and so a multiple regression analysis was run.

5.6.2. Regression analysis

The last objective of this study was to determine whether biographical factors (gender, age, employment, relationship status), clinical factors (MS sub-type), and coping strategies (Brief cope sub-scales) have an influence on the QoL of individuals with MS.

I sought to determine the predictors of QoL using a hierarchical multiple regression analysis. The predictors were organised into biographical predictors (gender, employment status, age, relationship status), clinical predictors (MS sub-types) and psycho-social predictors (coping strategies/ coping sub-scales). A hierarchical method was decided on since the selected independent variables were identified from the literature review (Field, 2013). The independent variables were added hierarchically in three blocks. In the first block biographical variables were added, then clinical in the second block, and the coping sub-scales were added in the third block. The order in which these variables were added was based on literature regarding QoL predictors in the MS population.

The results of the multiple regression analysis determined that the biographical (gender, employment status, age, relationship status) and clinical predictors (MS sub-types) were not significant predictors of QoL in this sample. However, the following coping sub-scales were found to be significant predictors of QoL: planning, positive reframing, acceptance, behavioural disengagement, and self-blame. Planning, positive reframing, and acceptance significantly influenced QoL positively, whereas behavioural disengagement and self-blame indicated a significant negative influence, as indicated in Table 5.11.

Moreover, the results specified that the model (Brief Cope scale) explained 58 % of the variance and that planning, positive reframing, acceptance, behavioural disengagement, and self-blame are significant predictors of QoL, *F*(19,175)=12.74, p<.05. This indicates that the following variables account for 58 % of the variance in the QoL score: planning (1.14 %), positive reframing (1.69%), acceptance (1.29 %), behavioural disengagement (1.23 %), and self-blame (9.85 %). The remaining variance (42.79 %) in the QoL score can be explained by the following variables: gender, age, employment, relationship status, MS sub-type and the Brief cope sub-scales 'self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, venting, humour, acceptance, and religion'. Table 5.11 summarizes the results of the hierarchical multiple regression analysis.

Table 5.11

Summary of Multiple Regression Analyses for Variables Predicting QoL

Model		B	Std. Error	Beta	t	sr^2	Sig.	R	R^2
1	(Constant)	45.51	9.78		4.66		.00	.13[a]	.02
	Age	.17	.16	.09	1.07	.00	.29		
	Gender	1.09	4.33	.02	.25	.00	.80		
	Relationship status	-2.53	1.99	-.09	-1.27	.01	.20		
	Employment	.39	.52	.06	.74	.00	.49		
2	(Constant)	47.35	9.64		4.91		.00	.23[b]	.05
	Age	.28	.16	.15	1.77	.02	.07		

	Gender	.48	4.27	.01	.11	.00	.91		
	Relationship status	-2.66	1.95	-.10	-1.36	.01	.17		
	Employment	.36	.51	.05	.70	.00	.48		
	MS sub-type	-3.10	1.16	-.19	-2.68	.001	.01*		
3	(Constant)	77.53	10.88		7.13		.00	.76[c]	.58
	Age	-.06	.12	-.03	-.54	.00	.59		
	Gender	-.36	3.01	-.01	-.12	.00	.91		
	Relationship status	-1.32	1.41	-.05	-.94	.00	.35		
	Employment	.09	.38	.01	.25	.00	.80		
	MS sub-type	-1.49	.85	-.09	-1.76	.01	.08		
	Planning	-1.82	.83	-.16	-2.19	.01	.03*		
	Active coping	.69	.89	.06	.79	.00	.43		
	Instrumental support	-.36	.74	-.03	-.48	.00	.63		
	Emotional support	.32	.66	.03	.49	.00	.62		
	Venting	-.15	.75	-.01	-.20	.00	.83		
	Positive reframing	1.7	.68	.17	2.64	.02	.01*		
	Acceptance	2.02	.87	.16	2.32	.01	.02*		
	Humour	.86	.57	.09	1.50	.01	.14		

Religion	.07	.50	.01	.14	.00	.89
Behavioural Disengagement	-1.78	.78	-.14	-2.27	.01	.03*
Mental Disengagement	-1.29	.72	-.11	-1.79	.00	.07
Denial	-1.39	.76	-.12	-1.81	.00	.07
Substance use	-.55	.67	-.05	-.82	.00	.41
Self-blame	-4.54	.71	-.43	-6.40	.09	.00*

Note. Constant (dependent variable): quality of life,

a. Predictors = Gender, Age, Employment, Relationship status

b. Predictors = Gender, Age, Employment, Relationship status, RRMS, PPMS, SPMS, PRMS

c. Predictors = Gender, Age, Employment, Relationship status, RRMS, PPMS, SPMS, PRMS, Active coping, Instrumental support, Emotional support, Venting, Positive reframing, Acceptance, Humour, Religion, Behavioural disengagement, Mental disengagement, Denial, Substance use, Self-blame

*$p < .05$

5.7. Conclusion

The results of the study were presented in this chapter. The biographical results and the descriptive statistics of the various measuring instruments were discussed. Next, the results of the correlation analysis regarding the relationship between coping and QoL were presented. Hereafter, the results from the multiple regression analysis were presented and discussed. Finally, the independent sample t-tests and one-way ANOVA’s were presented.

Chapter 6

Discussion

6.1. Introduction

The purpose of this study was to investigate the relationship between the coping strategies used by individuals with MS and their QoL in the context of South Africa. Although research on MS has increased globally throughout the years, there still remains a scarcity in the context of South Africa. This study therefore serves as a contribution to the literature, globally and in South Africa. With this being said, this study also aimed to contribute to literature on MS and QoL with the viewpoint on South Africa, which is a developing country in which it is possible that individuals with MS face unique barriers and stressors related to contextual, social, political and economic factors. The primary aim of this study was therefore to investigate the relationship between the coping strategies used by individuals with MS and their QoL in the context of South Africa.

In this chapter, I will discuss and interpret the results from the preceding chapter. I will start by providing a summary of the main findings obtained in this study. Thereafter, a discussion regarding the sample of participants included in this study will follow. I conclude this chapter with a discussion of important results that originated from this study, while integrating the theoretical framework (transactional theory on emotion and coping) and relevant literature.

6.2. Summary of main findings

The first objective of this study was to determine whether a relationship exist between the coping strategies used by individuals with MS and their QoL. The main findings here indicated that individuals who used emotional support, venting, positive reframing, and acceptance as coping strategies reported significantly higher QoL, as is often reported in research on MS and coping (Farran et al., 2016; Goretti et al., 2010, Kar et al., 2017; McCabe et al., 2004; Montel & Bungener, 2007). Moreover, the use of behavioural disengagement, mental disengagement, substance use, and self-blame as coping strategies equated to a poorer QoL among these participants with MS, a finding that is also often reported in research on MS (Gemmell et al., 2016; Hesselink et al., 2004; Yetwin, Mahrer, John, & Gold, 2018).

The second objective of this study was to ascertain whether male and female participants differ in terms of coping strategies used, by employing the Brief Cope questionnaire (Carver et al., 1989). The results showed that gender did not have a significant effect on the types of coping strategies utilised by this group of South Africans with MS. Again, this could be ascribed to the gender disparity among the participants, with 169 female participants and 31 male participants.

In addition, the third objective was to ascertain whether MS sub-types (RRMS, PRMS, SPMS, and PPMS) differ significantly in terms of the coping strategies used. The significant results showed that individuals with PPMS, used denial as a coping strategy more than those with RRMS (the least severe MS sub-type) and that MS sub-type has an influence on the coping strategies an individual with MS uses, as reported in numerous studies (Goretti et al., 2009; Lode et al., 2007; McCabe et al., 2003; Montel & Bungener, 2007).

Correspondingly, the fourth and fifth objective of this study was to ascertain if the males and females as well as MS sub-types (RRMS, PRMS, SPMS, and PPMS) significantly differ in terms of overall QoL score. Participants reported an overall low QoL score as well as low scores across all eight domains of the MusiQoL questionnaire (activities of daily living, psychological wellbeing, symptoms, relationships with friends, relationships with family, sentimental and sexual life, rejection, and relationship with healthcare system). These results indicate that MS has a negative effect on the QoL of individuals diagnosed with MS in South Africa, as is also reported in similar South African studies (Modi et al., 2008; Pretorius & Joubert, 2014) and in international research (Janardhan & Bakshi, 2002; Kes et al., 2013; McCabe & McKern, 2002; McCabe et al., 2009).

Gender differences were also found in QoL scores, with female participants reporting a slightly higher QoL than males in this study. Similarly, differences were found in the QoL between different MS sub-types, with RRMS having the highest QoL, higher satisfaction levels regarding daily activities, symptoms, and how they experience rejection compared to PRMS, SPMS, and PPMS. These differences are indicative that QoL is influenced by gender and disease severity as reported by several studies (Cioncoloni et al., 2014; Füvesi et al., 2010; Hopman et al., 2006; Kes et al., 2013; McCabe & McKern, 2002; Mitchell et al., 2005; Patti et al., 2007).

The last objective of this study was to determine whether biographical factors (gender, age, employment, relationship status), clinical factors (MS sub-type), and coping strategies (Brief cope sub-scales) have a significant influence on the QoL of individuals with MS. The significant results of this investigation indicated that planning, positive reframing, and acceptance had a significant positive influence on the QoL of individuals with MS in this study. In contrast, the use of behavioural disengagement and self-blame had a significant negative influence on individuals with MS. The positive and negative influence of various coping strategies on the QoL of individuals with MS is often reported in research (Farran et al., 2016; Goretti et al., 2009; Goretti et al., 2010; Montel & Bungener, 2007).

Thus, in line with previous research (e.g. Farran et al., 2016; Goretti et al., 2009; Goretti et al., 2010; McCabe et al., 2004; Mitchell et al., 2005), this study has demonstrated that coping strategies have an effect on MS diagnosed individuals' QoL. Moreover, that the use of coping strategies which are considered to be maladaptive (such as behavioural disengagement and self-blame) can adversely affect the QoL of individuals diagnosed with MS. This occurrence is further supported by Lazarus and Folkman's (1984; 1987) transactional theory on stress and coping, which argues that the coping strategies used by individual has an effect on their QoL.

6.3. MS participants included in the study

Participants included in this study were within the same age range as participants from other similar studies and had a similar age of onset of 20-40 years of age (Cross et al., 2011; Sand, 2015). The age range of this study is also in line with previous South African MS research which reported a participant age ranging from 28 to 71 years (Modi et al., 2008; Pretorius & Joubert, 2014). Similar to participants of other MS studies (Cross et al., 2011; Reipert, 2004; Sand, 2015), the majority of the participants in this study were females (n=169).

The majority of the participants in this study have been diagnosed with RRMS (73 %). A diagnosis of RRMS is commonly reported in MS research with an estimated 80% of individuals diagnosed with RRMS (Courtney et al., 2009; Reipert, 2004; Sand, 2015). Furthermore, PPMS was reported in 5.5 % of the sample as well as SPMS (5.5 %) and PRMS (5.5 %). These results are similar to what is reported in MS research as PPMS, SPMS, and PRMS are a lot less common than RRMS (Courtney et al., 2009; Reipert, 2004; Sand, 2015). The remaining participants (10.5 %) were unsure of their diagnosis. This uncertainty regarding their diagnosis could indicate that these participants have not been diagnosed with MS for a long period (i.e. not more than two years). Research suggests that the diagnosis of MS is often a broad and challenging process as there are no laboratory tests that lead to a definite diagnosis of MS (Pretorius & Joubert, 2014; Sand, 2015).

The biographical characteristics of this study were similar to other South African MS studies where the participants were mainly female, diagnosed with RRMS, and with the ages ranging from 28 to 71 years (Modi et al., 2008; Pretorius & Joubert, 2014; Pretorius 2016; Steadman & Pretorius, 2014). These data are therefore in keeping with MS data locally and globally in which participants were mainly female between the ages of 20 and 40 and diagnosed with RRMS (Courtney et al., 2009; Cross et al., 2011; Sand, 2015).

6.4. Relationship between coping and QoL

Extensive research has been done on the effect of coping and various coping strategies on the mental health and QoL of individuals with MS (e.g. Farran et al., 2016; Goretti et al., 2009; Goretti et al., 2010; McCabe et al., 2004; Mitchell et al., 2005). Furthermore, many researchers have indicated that there is a link between the use of coping strategies and one's QoL. More specifically, that certain coping strategies (such as seeking social support and planning) have a positive influence on an individuals QoL. On the other hand coping strategies such as behavioural disengagement, mental disengagement, self-blame and denial have a negative influence on one's QoL (McCabe et al., 2004; Montel & Bungener, 2007; Ledesma et al., 2018; Lode et al., 2007; Plow et al., 2009; Sanaeinasab et al., 2017). The first objective of this study was therefore to determine if a relationship exists between coping strategies used by individuals with MS and their QoL.

This study sought to investigate the possible influence of coping strategies (14 sub-scales of the Brief Cope measure) on the QoL (global index score) of individuals with MS. The results of this study found that a link exists between the coping strategies used by an individual and their QoL. More specifically significant positive correlations were identified between the coping sub-scales emotional support, venting, positive reframing, acceptance and QoL. These results indicate that individuals in this study whom rely on emotional support, venting, positive reframing, and acceptance as coping strategies reported significantly higher QoL, as is often reported in research on MS and coping (Farran et al., 2016; Goretti et al., 2010, Kar et al., 2017; McCabe et al., 2004; Montel & Bungener, 2007).

Regarding the relation between emotional support and QoL, research by various scholars (Farran et al., 2016; Ledesma et al., 2018) have identified a positive relationship between the use of emotional support, venting and QoL. For example, studies by Goretti et al. (2010) and Mikula et al. (2014) ascertained that when individuals with MS rely on emotional support and venting as coping strategies, enhanced adjustment, higher life satisfaction, reduced distress towards MS, and overall improved mental health is experienced.

Similarly, research by Lode et al. (2009), indicates that relying on coping strategies such as planning, positive reframing, and acceptance, especially during the early stages of MS (soon after diagnosis), has proven to be beneficial to patients. Patients who are newly diagnosed with MS are faced with a disease without a cure, and therefore perceive this as a stressful situation where little can be changed. These individuals then turn to coping strategies such as planning, positive reframing, and acceptance, to achieve emotion regulation (Lode et al., 2009).

In addition, significant negative correlations were found between QoL and the use of the coping strategies behavioural disengagement, mental disengagement, substance use, and self-blame. These results corroborate research on MS and coping that found that coping strategies that are intended to escape the problem at hand (such as behavioural disengagement, mental disengagement, substance use, self-blame) correlate with a poorer QoL (Gemmell et al., 2016; Hesselink et al., 2004; Yetwin, Mahrer, John, & Gold, 2018).

Various studies have reported on the negative effect of behavioural – and mental disengagement on the QoL of individuals with MS (Baslet, 2011; Farran et al., 2016; Goretti et al., 2009). For example, a recent study by Strober (2018) found that individuals with MS who reported low QoL levels, were reliant on coping strategies such as behavioural- and/or mental disengagement. The author deems these coping strategies as maladaptive due to their negative influence on the individuals' QoL (Strober, 2018). Besides a decrease in QoL, a study by Farran et al. (2016) found that individuals who rely on behavioural- and mental disengagement often report signs of depression and anxiety.

What is more, the negative correlation between QoL and the reliance on substance use and self-blame - as strategies to cope with MS- has also been reported in research (Caplan & Plioplys, 2010; Farren et al, 2016; Montel & Bungener, 2007). For example, a study by Caplan and Plioplys (2010) has found that the extensive use of coping strategies aimed at avoiding the problem through substance use and self-blame can lead to individuals with MS failing to pursue treatment. Not only has the reliance on such coping strategies been related to a decreased QoL, research by Farran et al. (2016), as well as Montel and Bungener (2007), found that such strategies lead to greater levels of distress, worse psychological adjustment, fatigue, and psychological ailments, such as depression and anxiety. From this discussion, it is evident that coping strategies have an influence on the QoL of individuals diagnosed with MS, which is corroborated by various authors (Caplan & Plioplys, 2010; Farren et al, 2016; Montel & Bungener, 2007; Strober 2018).

An association is therefore created between stress-related variables and outcomes related to health and well-being as the TTSC acknowledges that a causal relationship exists between coping and health (Lazarus & Folkman, 1984). In other words, "the quality of life and what we usually mean by mental and physical health are tied up with the ways people evaluate and cope with the stresses of living" (Lazarus & Folkman, 1984, p. 181). With this being said, maladaptive coping strategies (such as behavioural disengagement, mental disengagement, denial, substance use, and self-blame) have a negative impact on social functioning, morale/life satisfaction (QoL), and somatic health (Lazarus & Folkman, 1984).

6.5. Coping strategies amongst South Africans with MS

In defining the process of coping for this study, I drew on Lazarus and Folkman's (1984; 1987) transactional theory on emotion and coping. Lazarus and Folkman (1984; 1987) state that individuals use different coping strategies based on the different situations they find themselves in. This theory maintains that an individual will rely on coping strategies intended to directly address the problem more if he/she considers a threatening event as alterable. In the case of this study, the event will be that participants are diagnosed with MS. On the other hand, if the individual considers an event to be unalterable, he/she will look for opportunities to escape and will rely more on coping strategies that allow for this (Lazarus & Folkman, 1984; 1987). Based on the work of Lazarus and Folkman (1984), the Brief Cope questionnaire was devised to measure the coping strategies used by an individual. In exploring the coping strategies this sample uses, the Brief Cope questionnaire was utilised.

In this study, this sample of participants with MS relied on the coping strategy, acceptance (M=6.67), the most, and on the coping strategy, substance use (M=3.12), the least. The fact that the majority of participants made use of acceptance as a coping strategy could imply that this sample of MS participants view MS to be unalterable, and something that has to be endured/accepted, which can be explained by Lazarus and Folkman's (1984) model. Lazarus and Folkman (1984) argue that encounters that are unchangeable and demanding of tolerance are often associated with a greater use of coping strategies (such as acceptance) in which the individual acknowledges the reality of their unchangeable situation. This is understandable as MS is a chronic illness without a cure and can only be managed and not changed. Coping strategies aimed at escaping a threatening event (such as MS) has been reported frequently. For example, in a study by Ožura and Šega (2013) the authors reported that, when compared to healthy individuals, individuals with MS in their sample displayed a lower capability for coping with their MS and daily demands. The authors further noted that individuals with MS often turn to coping strategies that help them avoid a threatening event (such as MS). These coping strategies include mental and behavioural disengagement as well as denial (Ožura & Šega, 2013).

Lazarus (1999) argues that coping can be regarded as an individual’s reaction to manage stressful life conditions. Furthermore, a list of factors that influence individual coping with MS was compiled through a systematic review by Kar et al. (2017). Some of these factors will be discussed below in relation to this study.

6.5.1. Influence of gender and MS sub-type on coping

The second objective of this study was to determine if males and females significantly vary in terms of the coping strategies that they use. With regards to gender, the results of this study indicated small (but non-significant) differences between male and female coping variances. These results indicate that gender did not have a significant effect on the coping strategies that individuals with MS in this study used. These results are contradictory to what is often reported in research on individual differences between gender and QoL, which have found that females often report significantly higher QoL than males with MS (Holland et al., 2019; Kar et al., 2017; Mikula et al., 2014; Twork et al., 2007). These results can however be ascribed to fact that a great gender disparity exists with regards to the participants in this study, with 169 female participants and only 31 male participants.

The third objective of this study was to determine if MS sub-types (RRMS, PRMS, SPMS, and PPMS) differ significantly in terms of coping strategies used. The results of this investigation specified a significant difference between MS sub-types and the Brief Cope sub-scale, denial. Upon further investigation, a significant difference on the mean coping score of denial was indicated between the MS sub-types RRMS (M= 3.27, SD= 1.77) and PPMS (M=5.18, SD=2.75). No significant differences were found between the remaining MS sub-types, SPMS and PRMS. These results indicate that MS sub-type has an influence on the coping strategies utilised by individuals diagnosed with MS, as is widely reported in research (Lode et al., 2007; Mikula et al., 2014). It can therefore be argued that this sample of South Africans with RRMS and PPMS, rely on strategies (such as denial) to try and retain control over their lives through regulating the distressing emotions or avoiding the stressor altogether (Eschenbeck et al., 2007; Mikula et al., 2014).

The use of denial as a coping strategy amongst individuals with MS has been widely reported (Eschenbeck et al., 2007; Goretti et al., 2009; Goretti et al., 2010; Lode et al., 2007; Mikula et al., 2014). Moreover, research on MS reports that coping strategies such as denial are used more by participants with MS sub-types that cause more disabling symptoms such as PPMS (Lode et al., 2007; Mikula et al., 2014; Twork et al., 2007). A study by Lode et al. (2007) indicated that individuals who experience more disabling MS related symptoms (such as limb weakness, fatigue, pain and bowel, bladder, and sexual dysfunction), typically use coping strategies, such as denial to cope with the effect of MS on their health. Furthermore, the study by Lode et al. (2007) and Goretti et al. (2010) respectively found that individuals use strategies such as denial to help them detach mentally from the burden of living with MS. Again, these differences can possibly be attributed to disease severity as research indicates that increased disability due to MS often leads to an increased use of such coping strategies (Goretti et al., 2009; Lode et al., 2007).

From the aforementioned results and discussions, it is evident that MS sub-type has an influence on the coping strategies used by individuals with MS as displayed in numerous studies such as Eschenbeck et al. (2007), Goretti et al. (2010), McCabe and Di Battista (2004), Milanlioglu et al. (2014), Strober and Arnett (2014) etc.

6.6. QoL levels amongst South Africans with MS

The findings related to QoL in this study provides an indication of how this sample of South Africans with MS view their health, the impact it has on different aspects of their well-being and how this sample of individuals' QoL compares to individuals with MS from other countries. It also provides a suggestion of the areas in which this MS group experiences the least and most problems.

In this study QoL was evaluated by using the MusiQoL questionnaire. The results of this study indicate a low overall QoL score (M=51.33) as well as low domain scores (activities of daily living, psychological wellbeing, symptoms, relationships with friends, relationships with family, sentimental and sexual life, rejection, and relationship with healthcare system) for this sample.

Similar findings were reported in previous research that sought to determine QoL levels amongst individuals with MS. These studies all stated that individuals with MS report low QoL levels (Janardhan & Bakshi, 2002; Kes et al., 2013; McCabe & McKern, 2002; McCabe, Stokes,

& McDonald, 2009). For example, the study by McCabe et al. (2009) investigated the QoL of 382 Australians with MS. The results of this study showed that this sample has low QoL levels, as measured by the World Health Organization Quality of Life-100 scale (McCabe et al., 2009). Similarly, results from the study by Montel and Bungener (2006) on 135 French MS patients indicated lower scores on all the dimensions of QoL as measured by the SEP59.

In line with Lazarus and Folkman's (1984; 1987) transactional theory of stress and coping, the coping strategies (behavioural disengagement and self-blame) used by this group of individuals with MS could account for some, but not all, of the low QoL levels reported. Literature suggests that the low QoL levels amongst MS patients could be ascribed to certain features of MS. These features include MS age of onset (usually during the prolific days of one's life), the unpredictability of MS, the physical and social limitations due to CNS damage, and the absence of a cure (Füvesi et al., 2010; Kes et al., 2013; Motl et al., 2013). Research also indicates that physical disabilities (which lead to lessened autonomy), decreased social support, and psychological ailments are related to a lower life satisfaction (and QoL) amongst individuals with MS (Füvesi et al., 2010; Kes et al., 2013; Motl et al., 2013).

In ascertaining what the QoL of individuals with MS in this sample was, it was also necessary to look at each of the QoL domains. It is important to note that the MusiQoL is made up of nine domains, but that this study only made use of eight. Similar to the overall QoL score, these domains can be scored from 0-100, with a higher score representing an enhanced QoL (Fernández et al., 2011). The mean scores of the 8 QoL domains revealed that this sample scored the rejection domain (M=73.63) the highest. Participants scored the sentimental and sexual life domain (M=43.97) the lowest, followed by activities of daily living (M=47.23), relationships with friends (M=47.67), psychological wellbeing (M=47.75), and symptoms (M=48.97). These low scores indicate that participants in this study reported low QoL and satisfaction with regards to sentimental and sexual life, relationships with friends, psychological wellbeing, and MS symptoms. These results are thus similar to what is reported in research as participants in this study rated activities related to physical movement, social contributors (such as social support), psychological wellbeing, and symptoms related to MS the lowest (Hopman et al., 2006; Montel & Bungener, 2006; Patti et al., 2007).

6.6.1. Influence of gender and MS sub-type on QoL

In this study I sought to determine if gender and MS sub-type had an influence on the QoL of the participants in this sample. With this being said, the fourth and fifth objective of this study was to ascertain whether males and females and MS sub-types (RRMS, PRMS, SPMS, and PPMS) differ significantly in terms of overall QoL score.

With regards to gender, small (but non-significant) differences were found in the QoL scores of male (M=50.20) and female (M=51.54) participants. This indicates that female participants in this study reported a slightly higher QoL than their male counterparts. This notion is often reported in research on MS which states that males with MS have been reported to experience a lower QOL than females (McCabe et al., 2009).

As with coping, research shows that QoL is influenced by disease severity (Cioncoloni et al., 2014; Füvesi et al., 2010; Kes et al., 2013; McCabe & McKern, 2002; Mitchell et al., 2005). In this sample the QoL of the MS sub-type RRMS (M =54.66) was the highest, followed by PRMS (M= 44.55), SPMS (M =37.75), and PPMS (M =33.30). Participants with RRMS therefore had the highest QoL. In line with previous research, individuals within the RRMS sub-type, which is the least-severe type, often report higher QoL levels compared to the other types (Benito-León et al., 2003; Füvesi et al., 2010; Kes et al., 2013).

Further investigation indicated that significant differences were found between the mean QoL scores (global index score) and the MS sub-types, RRMS and PRMS. These differences indicate that MS sub-type has an effect on the QoL of an individual. Individuals with a progressive course (PRMS) of disease, compared to those with a relapse-remitting course (RRMS), experience increased physical disability and upper-extremity function is often severely restricted. Research shows that restrictions due to MS correlate with a decrease in QoL (Van Schependom et al., 2014; Yozbatiran et al., 2006). The results of this study are therefore in line with research which found that QoL decreases with increasing disease severity (Benito-León et al., 2003; Füvesi et al., 2010; Van Schependom et al., 2014; Yozbatiran et al., 2006). In their study, Benito-León et al. (2003) found that, the more aggressive the disease course of MS, the lower the individuals' QoL.

Regarding the specific sub-scales of the MusiQoL instrument, significant differences were reported between RRMS and three sub-scales, namely activities of daily living, symptoms, and rejection. Significant differences were also found between PPMS and activities of daily living, symptoms, and rejection. No significant differences were found between the MS sub-types, SPMS and PRMS, and the MusiQoL sub-scales. These differences indicate that, as disease severity increases, life satisfaction decreases in activities of daily living, symptoms, relationship with the healthcare system, and rejection the most. Each of these sub-scales will be discussed in detail in the following paragraphs.

Much of the research on MS highlights the difficulties individuals face due to physical restrictions and MS symptoms (Füvesi et al., 2010; Kes et al., 2013; Motl et al., 2013). These restrictions and symptoms make it more difficult for individuals with MS to perform their daily tasks and activities, and often leads to social withdrawal (Hopman, Coo, Edgar, McBride, Day,

& Brunet, 2007). The results of a study by Füvesi et al. (2010) indicated that their sample of 400 Hungarian individuals with MS reported satisfaction with their overall physical health the lowest.

MS not only affects an individual physically, as a study by Benedict et al., (2005) reports that those diagnosed with MS experience a loss of personal identity, psychological ailments (depression and anxiety), as well as feelings of dependency. With this being said, in many cases individuals with MS become isolated and feel rejected. The loss of employment further contributes to the feelings of rejection and dependency (Strober & Arnett, 2016). As mentioned previously, Strober and Arnett (2016) found that between 56 and 80% of individuals are unemployed due to their MS.

The findings from this study therefore highlight the most prevalent problems expressed by many individuals with MS as found by previous research (Baumstarck et al., 2016; Füvesi et al., 2010; Kes et al., 2013; Hopman et al.,2007; Motl et al., 2013). These findings are similar to research which states that physical disabilities, decreased social support, and psychological ailments are most often associated with a lower QoL among individuals with MS (Füvesi et al., 2010; Kes et al., 2013; Motl et al., 2013).

The low score on the QoL measure (MusiQoL) and on all eight of the QoL domains highlight the physical and psychological difficulties that patients with MS experience. In line with previous research, the findings of this study highlight the importance of the use of QoL as an important measure for therapeutic outcomes (LaFrance & Syc, 2009). Furthermore, as highlighted in a study by Mitchell et al. (2005), QoL can be used to make health professionals more attentive to the less obvious burdens of MS (such as fatigue, sexual dysfunctions, depression, and anxiety).

From the discussion above, it is evident that MS has a significant negative impact on the QoL of individuals. These findings also suggest that MS influences every aspect of a patient's life, and each in a different manner. Moreover, results from this study indicates that the QoL scores of individuals with MS in South Africa is similar to other studies on MS and QoL that were conducted in other countries such as Europe, North America, Italy, Canada, and France (Dua & Rompani, 2008; Lera et al., 2016; Simeoni et al., 2008; Patti et al., 2007).

6.6.2. Factors influencing QoL amongst MS individuals

The last objective of this study was to investigate if biographical factors (gender, employment status, age, and marital status), clinical factors (MS sub-type), and coping strategies (Brief cope sub-scales) have a significant influence on the QoL of individuals with MS.

The results of the multiple regression analysis determined that the biographical (gender, employment status, age, relationship status) and clinical predictors (MS sub-types) were not significant predictors of QoL in this sample. However, the following coping sub-scales were found to be significant predictors of QoL among the participants in this study: planning, positive reframing, acceptance, behavioural disengagement, and self-blame. Here, it was specified that planning, positive reframing, and acceptance significantly influenced QoL positively. This result, along with that of other studies, indicates that as an individual with MS relies on planning, positive reframing, and acceptance more, their QoL increases (Kar et al., 2017; McCabe et al., 2004; Montel & Bungener, 2007).

Furthermore, behavioural disengagement and self-blame were found to have a significant negative influence on QoL. This shows that, the more an individual with MS relies on behavioural disengagement and self-blame as coping strategies, the worse their QoL will be as was also reported in research by Baslet (2011), Farran et al. (2016) and Goretti et al., (2009) respectively.

The results of this study further determined that the model explained 58 % of the variance in the QoL. This indicates that the following variables account for 58 % of the variance in the QoL score: planning (1.14 %), positive reframing (1.69%), acceptance (1.29 %), behavioural disengagement (1.23 %), and self-blame (9.86 %). The remaining variance (42.79 %) in the QoL score can be explained by the following variables: gender, age, employment, relationship status, MS sub-type and the Brief cope sub-scales 'self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, venting, humour, acceptance, and religion'.

There are various studies, on MS and coping, that provide an explanation for the positive influence of planning, positive reframing, and acceptance on individuals' QoL (for example Farran et al., 2016; Goretti et al., 2010, Kar et al., 2017; McCabe et al., 2004; Montel & Bungener, 2007). The reliance on planning, positive reframing, and acceptance as coping strategies by participants in this study could be related to the fact that these coping strategies are often used by individuals with MS in the early stages of the illness (Farran et al., 2016; Goretti et al., 2010, Kar et al., 2017; McCabe et al., 2004; Montel & Bungener, 2007). A study by Mikula et al. (2014) argue that by acknowledging and stopping unpleasant emotions (through planning, positive reframing, and acceptance) these coping strategies act as adaptive measures. Since individuals diagnosed with MS have little control over their diagnosis, they have to learn to live with the disease. This is then achieved by accepting their diagnosis and framing negative emotions into a positive manner (positive reframing), which is related to a reduction in stress, improved mental health, and improved QoL (Mikula et al., 2014).

In this study, the reliance on acceptance, behavioural disengagement, and self-blame as coping strategies can be explained by Lazarus and Folkman's (1984) model. If this theory is aligned with an individual with MS, it can be argued that, when receiving a diagnosis of MS, an individual might be overcome with emotions of stress and fear. Since MS is a chronic disease without a cure, this individual might appraise this situation as surpassing his/her resources and compromising his/her well-being. In order to cope with this situation, this individual might rely on coping strategies (such as acceptance, behavioural disengagement, or self-blame), because their situation/diagnosis is unchangeable. If these coping strategies are not a correct fit, the individual might experience a negative sense of well-being in the long run, due to ineffective coping. Evidently, the way in which an individual chooses to cope with a stressful situation (for example MS) can influence their QoL (Lazarus & Folkman, 1984).

Furthermore, the negative influence of the coping strategies, behavioural disengagement and self-blame, on the QoL of participants with MS in this study, has also been widely reported in MS research (Baslet, 2011; Farran et al., 2016; Goretti et al., 2009). For instance, a study by Baslet (2011), found that coping strategies aimed at avoiding the problem at hand (such as behavioural -, mental disengagement and self-blame) is related with increased psychological distress and lower QoL, since individuals neglect to express their emotions and leave them unresolved. By leaving emotions unresolved, patients' health and overall QoL is negatively affected (De Ridder, Geenen, Kuijer & van Middendorp, 2008; Taylor, 2006).

From the above discussion it is evident that coping styles play a key role in QoL. The manner in which an individual adapts to MS also depends on the effectiveness of the coping style they employ. Coping strategies (such as emotional support, planning, positive reframing, and acceptance) have been cited in the research literature as significant concepts in maintaining and/or improving QoL in individuals with MS (Kar et al., 2016). In contrast, ineffective coping (through the use of coping strategies such as behavioural disengagement, substance use, and self-blame) has been related to many additional negative influences such as, an increase in MS and symptom exacerbations, greater levels of distress, worse psychological adjustment, fatigue, and psychological ailments (De Ridder et al., 2008 Kar et al., 2017; Hesselink et al., 2004; McCabe et al., 2009). In this study, individuals who rely on the coping strategies behavioural disengagement and self-blame also reported low QoL levels. These results are inline with Lazarus and Folkman's transactional theory of stress and coping, confirm findings from previous studies (e.g. Baslet, 2011; De Ridder et al., 2008; Farran et al., 2016; Montel and Bungener, 2007; Taylor, 2006) and highlight the crucial importance of factors that are amenable to change, such as coping (Janzen, Turpin, Warren, Marrie, & Warren, 2013).

6.7. Conclusion

In this chapter I interpreted and discussed the results from the biographical, coping (Brief Cope), and QoL (MusiQoL) questionnaires. Thereafter, I provided a summary of the main findings obtained in this study. I concluded this chapter with a discussion of important results that originated from this study. This discussion was integrated with the theoretical framework (transactional theory on emotion and coping) used in this study and relevant literature.

Chapter 7

Conclusion

7.1. Introduction

In this chapter I will present the strengths of this study. Next, I will discuss some limitations and recommendations for future research relating to this topic. Subsequently, I will present the significance of the present study and concluding comments.

7.2. Strengths of this study

Certain strengths of this study have to be considered when interpreting the results. Firstly, this study made use of a relatively representative sample, as participants were recruited from the organisation, Multiple Sclerosis South Africa Western Cape’s online Facebook support group. The members of this support group (*n* = 3000) come from many different demographic and socio-economic backgrounds from all over South Africa, which resulted in a diverse sample of participants.

Moreover, this study supports previous findings, which suggest that individuals with MS are more likely to use maladaptive coping strategies (such as isolation, denial, disengagement, and substance use) to cope with MS (Farran et al., 2016; Goretti et al., 2010, Kar et al., 2017; McCabe et al., 2004; Montel & Bungener, 2007).

Another strength of this study is the fact that there is no other research evidence available regarding coping strategies and QoL in relation to MS in the context of South Africa. This study is therefore unique and contributes to the need for South African research regarding coping and QoL amongst individuals with MS.

7.3. Limitations of the present study

Some limitations should be considered when interpreting these results. Firstly, a limitation of the present study is the fact that the sample was made up of mostly female participants. Although this gender disparity is representative of the MS sample (Cross et al., 2011; Reipert, 2004), results should be interpreted with caution.

A second limitation would be the fact that this study was a cross-sectional study. Problems with non-responses on surveys are often reported (Levin, 2006), as was the case in this study where the population size (n= 3000) was much bigger than the actual sample size (n = 200). Another disadvantage often reported with the use of cross-sectional research, is the fact that data obtained from such research may provide different results if another timeframe had been chosen (Sedgwick, 2014).

Another limitation of this study could be the dependence on self-reported measures to measure coping strategies and QoL, as these may not reflect participant's actual behaviour. The last limitation occurred as a result of some questions being left blank throughout the survey, leading to participant exclusion on some analyses.

7.4. Recommendations for future studies

Future studies wishing to recreate or use the data created by this study may possibly keep the following recommendations in mind. The limitation of gender disparity (mostly female participants) reported in this study could be overcome by using a larger sample size, with more male participants. The larger sample size could lessen the gender disparity reported in this study.

Secondly, this study could be recreated by utilising other sampling strategies or a combination thereof (such as structured interviews and/or quota sampling). The use of a different sampling strategies could lead to a bigger sample size, improved response rates, and a better representation of individuals with MS.

Lastly, for studies who wish to replicate this study, it may be advantageous to review the settings on the online questionnaire and set it to make all or a larger percentage of the questions necessary to complete. This could lessen participant exclusion on the data analyses, and lead to more reliable and representative results. Future research can thus explore this relationship between coping and QoL, which could be promising for improving treatment for the debilitating symptoms of MS.

7.5. Conclusion

This study produced some important trends regarding MS, coping and QoL in the context of this sample of South Africans with MS. It was discovered that a relationship exists between coping and QoL, as well as between the use of emotion-focused and avoidance coping strategies and a low QoL.

This study also identified areas that individuals with MS in South Africa struggle the most with. Seeing that South Africa is a developing country in which the possibility exists that South Africans with MS face unique barriers and stressors associated with their contextual, social, political and economic factors, this study adds to the limited research available in South Africa. The trends produced by this study can be investigated and used to inform therapeutic services through exploring the factors (activities of daily living, psychological wellbeing, symptoms, relationships with friends, sentimental and sexual life) this sample of MS participants highlighted as most troubling.

This study therefore sheds light on the coping strategies individuals with MS in South Africa typically use, as well as the strategies that are associated with low levels of QoL. Research suggests that, by identifying coping strategies that have a positive influence on QoL, the disease-burden experienced by individuals with MS could be decreased. These findings are therefore important for orientating future therapeutic interventions aimed at altering factors (that can be changes) to increase individuals with MS's QoL (McCabe et al., 2004; Montel & Bungener, 2007; Plow et al., 2009; Sanaeinasab et al., 2017). This study also supports previous research findings in which individuals with MS rely more on coping strategies such as behavioural disengagement, mental disengagement, substance use, and self-blame to avoid stressful events (Farran et al., 2016; Goretti et al., 2010, Kar et al., 2017; McCabe et al., 2004; Montel & Bungener, 2007). Future studies should aim to examine coping in more detail, as it would help to provide valuable information on what forms of coping should be encouraged for overall improved QoL among South Africans with MS. The findings of this study provided greater insight into the patterns of coping and QoL of individuals with MS in South Africa. These findings also highlight that the type of coping strategies (for example denial, acceptance, behavioural disengagement, and self-blame) used by the MS participants in our sample had a significant negative influence on their level of QoL.

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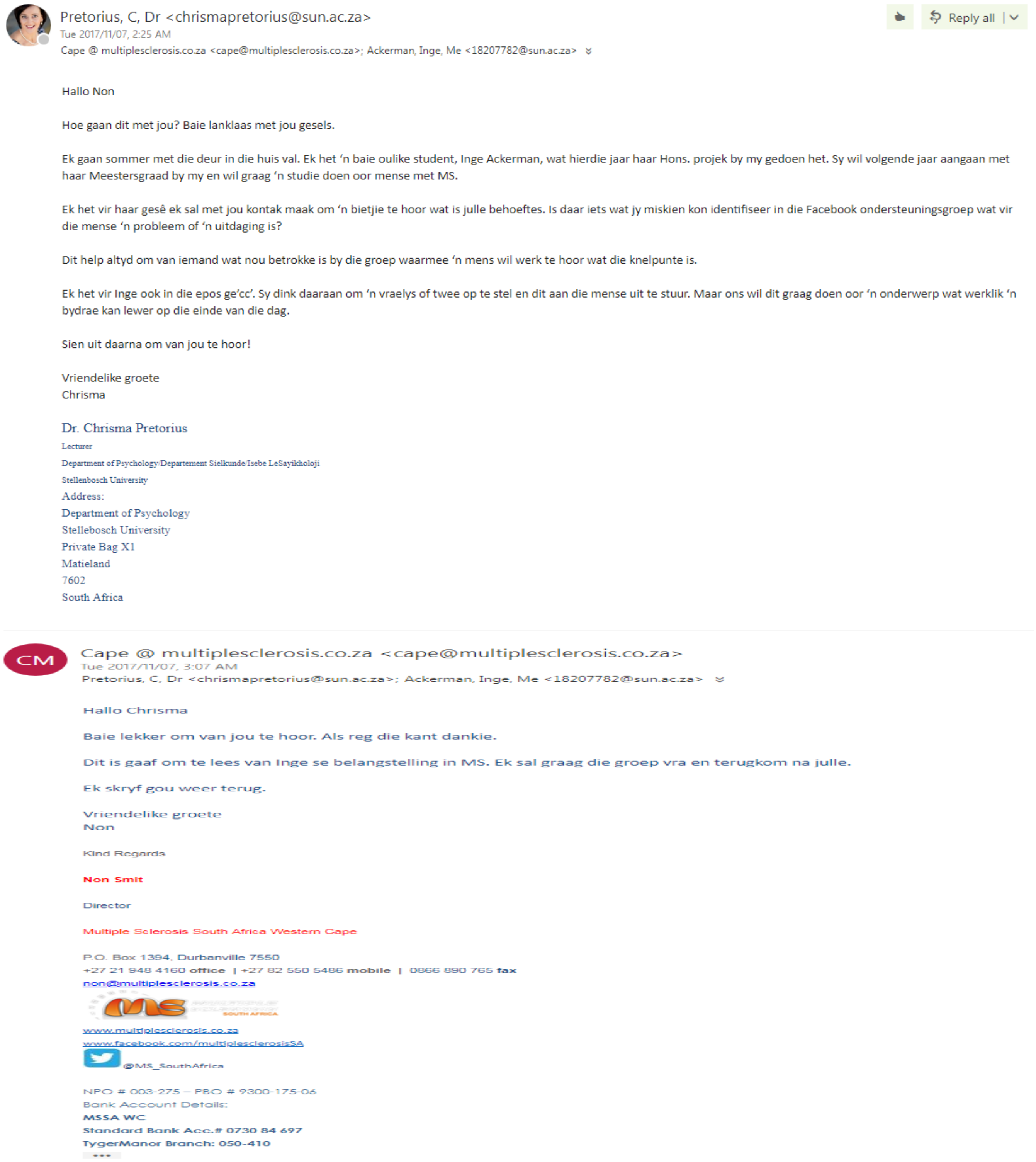
Appendices

Appendix A: Permission to make use of Multiple Sclerosis South Africa Western Cape's online Facebook support group



Pretorius, C, Dr <chrismapretorius@sun.ac.za>
Tue 2017/11/07, 2:25 AM
Cape @ multiplesclerosis.co.za <cape@multiplesclerosis.co.za>; Ackerman, Inge, Me <18207782@sun.ac.za>

Hallo Non

Hoe gaan dit met jou? Baie lanklaas met jou gesels.

Ek gaan sommer met die deur in die huis val. Ek het 'n baie oulike student, Inge Ackerman, wat hierdie jaar haar Hons. projek by my gedoen het. Sy wil volgende jaar aangaan met haar Meestersgraad by my en wil graag 'n studie doen oor mense met MS.

Ek het vir haar gesê ek sal met jou kontak maak om 'n bietjie te hoor wat is julle behoeftes. Is daar iets wat jy miskien kon identifiseer in die Facebook ondersteuningsgroep wat vir die mense 'n probleem of 'n uitdaging is?

Dit help altyd om van iemand wat nou betrokke is by die groep waarmee 'n mens wil werk te hoor wat die knelpunte is.

Ek het vir Inge ook in die epos ge'cc'. Sy dink daaraan om 'n vraelys of twee op te stel en dit aan die mense uit te stuur. Maar ons wil dit graag doen oor 'n onderwerp wat werklik 'n bydrae kan lewer op die einde van die dag.

Sien uit daarna om van jou te hoor!

Vriendelike groete
Chrisma

Dr. Chrisma Pretorius
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Tue 2017/11/07, 3:07 AM
Pretorius, C, Dr <chrismapretorius@sun.ac.za>; Ackerman, Inge, Me <18207782@sun.ac.za>

Hallo Chrisma

Baie lekker om van jou te hoor. Als reg die kant dankie.

Dit is gaaf om te lees van Inge se belangstelling in MS. Ek sal graag die groep vra en terugkom na julle.

Ek skryf gou weer terug.

Vriendelike groete
Non

Kind Regards

Non Smit

Director

Multiple Sclerosis South Africa Western Cape

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Appendix B: Information about the study will be posted to the Facebook support group

My name is Inge Ackerman, and I am a master’s student at Stellenbosch University. People with MS often use different coping strategies to cope with the unpredictable course of MS and these coping strategies often affect their quality of life. I am seeking your help on a research project to understand what the relationship is between the coping styles used by people with multiple sclerosis and their quality of life (QoL) in South Africa. If you are interested in taking part in this study, please follow this link (hyperlink) which will give you more information about this study and give you access to an anonymous survey.

Thank you in advance for your help.

Appendix C: Participant information leaflet and consent form for online surveys/questionnaires

TITLE OF RESEARCH PROJECT: COPING STYLES AND QUALITY OF LIFE IN PATIENTS WITH MULTIPLE SCLEROSIS (MS): A SOUTH AFRICAN PERSPECTIVE

We would like to invite you to take part in a research project, which involves the completion of an online questionnaire. Your participation is **entirely voluntary** and you are free to decline to participate or to stop completing the questionnaire at any time, even if you have agreed to take part initially. However, once you have submitted your completed questionnaire online, you will no longer be able to withdraw your responses, as there will be no way of linking your responses back to you (due to the anonymous nature of the survey).

What is the study about?

- This study wants to find out which coping strategies individuals with multiple sclerosis typically use and how these influence their quality of life. This study also wants to find out what the typical quality of life levels of individuals with multiple sclerosis are.
- This study is important because effective coping with multiple sclerosis can be beneficial to individuals with MS's overall quality of life.
- This study will be conducted by Inge Ackerman, a master's student at Stellenbosch University, and will include approximately 350 participants.
- If you agree to participate in this study, you will be asked to fill out a questionnaire, which contains questions that can be answered by ticking a box.

Why are you being asked to participate?

- You are over the age of 18, and have been diagnosed with multiple sclerosis by a health professional.

What will participating in the study entail?

- If you agree to take part in this study, you will be asked to fill out a questionnaire containing three different components that will take approximately 25 minutes to complete.
- Firstly, you will be asked to fill out a biographical survey (taking approximately 5 minutes to complete). This survey contains questions such as “What is your age?”, “What is your gender?”, “What is your current employment status?” and “Approximately how many years have you been diagnosed with multiple sclerosis?”.
- Secondly, you will be asked to fill out a survey regarding coping behaviours (taking approximately 10 minutes to complete). This survey will include statements such as “I've been turning to work or other activities to take my mind off things.” and “I've been giving up trying to deal with it.”
- Lastly, you will be asked to fill out a questionnaire, which deals with your quality of life (QoL), and this will take approximately 10 minutes to complete. This survey will include questions such as “Have you had difficulty walking or moving outside?” and “Have you been quickly tired?”.
- You will only be asked to answer these questions once, and they can be filled out online using the link provided to you. No identifying particulars such as your name, telephone numbers, or email addresses will be asked.

Will you benefit from taking part in this research?

- Whilst there are no immediate or direct benefits for those people participating in the study, it is hoped that this work will help us in understanding more about what individuals with multiple sclerosis have to live with.
- By participating in this study, you are contributing to the knowledge on multiple sclerosis that can benefit research aimed regarding important aspects of multiple sclerosis such as coping and quality of life. This information can contribute to inform treatment and therapy.

Are there any risks involved in your taking part in this research?

- We foresee no risks by taking part in this study.
- You will not be asked to provide your name in this study. The answers that you provide through the questionnaire can be given anonymously, so no information that you provide us with will be able to be traced back to you.
- All the information that we collect about you during the course of the research will be kept strictly confidential, through saving the data set on a computer that is protected with a password, which only my supervisors (Dr Chrisma Pretorius (supervisor) and Dr Bronwyne Coetzee (co-supervisor)) and I will have access to.
- You will not be able to be identified in any reports or publications.
- The answers you provide will not be seen by anyone, except myself, my supervisor Dr Chrisma Pretorius, and co-supervisor Dr Bronwyne Coetzee.

You can phone the Principal Investigator of this study, Inge Ackerman at 0718813201 and 18207782@sun.ac.za if you have any questions about this study or encounter any problems. Alternatively, you can contact the supervisor, Dr Chrisma Pretorius on chrismapretorius@sun.ac.za and the co-supervisor, Dr Bronwyne Coetzee on bronwyne@sun.ac.za.

The Health Research Ethics Committee at Stellenbosch University has approved this study**.** The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

You can phone the Health Research Ethics Committee at 021 938 9677/9819 if there still is something that concerns you about how this study is being conducted, or if you have a complaint.

You will receive a copy of this information and consent form for you to keep safe.

By clicking START SURVEY you are confirming that you are over 18 years old and have read and understood the above explanation about the study, and that you agree to participate. You also understand that your participation in this study is voluntary.

Appendix D: Biographical questionnaire

1. Age (Please fill in)

   ____

2. Gender
   - ☐ Male
   - ☐ Female
   - ☐ Other

3. What is your marital status?
   - ☐ Single (never married)
   - ☐ Married, or in a domestic partnership
   - ☐ Widowed
   - ☐ Divorced
   - ☐ Separated

4. What is your current employment status?
   - ☐ Employed full time (40 or more hours per week)
   - ☐ Employed part time (up to 39 hours per week)
   - ☐ Unemployed and currently looking for work
   - ☐ Unemployed and not currently looking for work
   - ☐ Student
   - ☐ Retired
   - ☐ Homemaker
   - ☐ Self-employed
   - ☐ Unable to work

5. Have you been diagnosed with multiple sclerosis (MS) by a health professional?
   - ☐ Yes
   - ☐ No

6. Approximately how many years have you been diagnosed with multiple sclerosis?

- ☐ Less than a year
- ☐ 1-5 years
- ☐ 5-10 years
- ☐ more than 10 years

7. What type of multiple sclerosis (MS) are you diagnosed with?
    - ☐ Relapsing/remitting MS (RRMS)
    - ☐ Primary progressive MS (PPMS)
    - ☐ Secondary progressive MS (SPMS)
    - ☐ Progressive relapsing MS (PRMS)
    - ☐ Not sure

Appendix E: Brief COPE questionnaire

These items deal with ways you have been coping with the stress in your life since you found out you were going to have to have this operation. There are many ways to try to deal with problems. These items ask what you have been doing to cope with this one. Obviously, different people deal with things in different ways, but I am interested in how you have tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you have been doing what the item says. How much or how frequently. Do not answer based on whether it seems to be working or not—just whether or not you are doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

Ratings:

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

Questions:

1. I've been turning to work or other activities to take my mind off things.
    - ☐ 1 I haven't been doing this at all
    - ☐ 2 I've been doing this a little bit
    - ☐ 3 I've been doing this a medium amount
    - ☐ 4 I've been doing this a lot
2. I've been concentrating my efforts on doing something about the situation I'm in.
    - ☐ 1 I haven't been doing this at all
    - ☐ 2 I've been doing this a little bit
    - ☐ 3 I've been doing this a medium amount

- ☐ 4 I've been doing this a lot

3. I've been saying to myself "this isn't real.".
   - ☐ 1 I haven't been doing this at all
   - ☐ 2 I've been doing this a little bit
   - ☐ 3 I've been doing this a medium amount
   - ☐ 4 I've been doing this a lot
4. I've been using alcohol or other drugs to make myself feel better.
   - ☐ 1 I haven't been doing this at all
   - ☐ 2 I've been doing this a little bit
   - ☐ 3 I've been doing this a medium amount
   - ☐ 4 I've been doing this a lot
5. I've been getting emotional support from others.
   - ☐ 1 I haven't been doing this at all
   - ☐ 2 I've been doing this a little bit
   - ☐ 3 I've been doing this a medium amount
   - ☐ 4 I've been doing this a lot
6. I've been giving up trying to deal with it.
   - ☐ 1 I haven't been doing this at all
   - ☐ 2 I've been doing this a little bit
   - ☐ 3 I've been doing this a medium amount
   - ☐ 4 I've been doing this a lot
7. I’ve been taking action to try to make the situation better.
   - ☐ 1 I haven't been doing this at all
   - ☐ 2 I've been doing this a little bit
   - ☐ 3 I've been doing this a medium amount
   - ☐ 4 I've been doing this a lot
8. I've been refusing to believe that it has happened.
   - ☐ 1 I haven't been doing this at all

☐ 2 I've been doing this a little bit
☐ 3 I've been doing this a medium amount
☐ 4 I've been doing this a lot

9. I've been saying things to let my unpleasant feelings escape.

☐ 1 I haven't been doing this at all
☐ 2 I've been doing this a little bit
☐ 3 I've been doing this a medium amount
☐ 4 I've been doing this a lot

10. I’ve been getting help and advice from other people.

☐ 1 I haven't been doing this at all
☐ 2 I've been doing this a little bit
☐ 3 I've been doing this a medium amount
☐ 4 I've been doing this a lot

11. I've been using alcohol or other drugs to help me get through it.

☐ 1 I haven't been doing this at all
☐ 2 I've been doing this a little bit
☐ 3 I've been doing this a medium amount
☐ 4 I've been doing this a lot

12. I've been trying to see it in a different light, to make it seem more positive.

☐ 1 I haven't been doing this at all
☐ 2 I've been doing this a little bit
☐ 3 I've been doing this a medium amount
☐ 4 I've been doing this a lot

13. I’ve been criticizing myself.

☐ 1 I haven't been doing this at all
☐ 2 I've been doing this a little bit
☐ 3 I've been doing this a medium amount
☐ 4 I've been doing this a lot

14. I've been trying to come up with a strategy about what to do.

  ☐ 1 I haven't been doing this at all
  ☐ 2 I've been doing this a little bit
  ☐ 3 I've been doing this a medium amount
  ☐ 4 I've been doing this a lot

15. I've been getting comfort and understanding from someone.

  ☐ 1 I haven't been doing this at all
  ☐ 2 I've been doing this a little bit
  ☐ 3 I've been doing this a medium amount
  ☐ 4 I've been doing this a lot

16. I've been giving up the attempt to cope.

  ☐ 1 I haven't been doing this at all
  ☐ 2 I've been doing this a little bit
  ☐ 3 I've been doing this a medium amount
  ☐ 4 I've been doing this a lot

17. I've been looking for something good in what is happening.

  ☐ 1 I haven't been doing this at all
  ☐ 2 I've been doing this a little bit
  ☐ 3 I've been doing this a medium amount
  ☐ 4 I've been doing this a lot

18. I've been making jokes about it.

  ☐ 1 I haven't been doing this at all
  ☐ 2 I've been doing this a little bit
  ☐ 3 I've been doing this a medium amount
  ☐ 4 I've been doing this a lot

19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.

  ☐ 1 I haven't been doing this at all
  ☐ 2 I've been doing this a little bit

☐ 3 I've been doing this a medium amount
☐ 4 I've been doing this a lot

20. I've been accepting the reality of the fact that it has happened.

☐ 1 I haven't been doing this at all
☐ 2 I've been doing this a little bit
☐ 3 I've been doing this a medium amount
☐ 4 I've been doing this a lot

21. I've been expressing my negative feelings.

☐ 1 I haven't been doing this at all
☐ 2 I've been doing this a little bit
☐ 3 I've been doing this a medium amount
☐ 4 I've been doing this a lot

22. I've been trying to find comfort in my religion or spiritual beliefs.

☐ 1 I haven't been doing this at all
☐ 2 I've been doing this a little bit
☐ 3 I've been doing this a medium amount
☐ 4 I've been doing this a lot

23. I’ve been trying to get advice or help from other people about what to do.

☐ 1 I haven't been doing this at all
☐ 2 I've been doing this a little bit
☐ 3 I've been doing this a medium amount
☐ 4 I've been doing this a lot

24. I've been learning to live with it.

☐ 1 I haven't been doing this at all
☐ 2 I've been doing this a little bit
☐ 3 I've been doing this a medium amount
☐ 4 I've been doing this a lot

25. I've been thinking hard about what steps to take.

☐ 1 I haven't been doing this at all

- ☐ 2 I've been doing this a little bit
- ☐ 3 I've been doing this a medium amount
- ☐ 4 I've been doing this a lot

26. I’ve been blaming myself for things that happened.

- ☐ 1 I haven't been doing this at all
- ☐ 2 I've been doing this a little bit
- ☐ 3 I've been doing this a medium amount
- ☐ 4 I've been doing this a lot

27. I've been praying or meditating.

- ☐ 1 I haven't been doing this at all
- ☐ 2 I've been doing this a little bit
- ☐ 3 I've been doing this a medium amount
- ☐ 4 I've been doing this a lot

28. I've been making fun of the situation.

- ☐ 1 I haven't been doing this at all
- ☐ 2 I've been doing this a little bit
- ☐ 3 I've been doing this a medium amount
- ☐ 4 I've been doing this a lot

Appendix F: Multiple Sclerosis International Quality of Life questionnaire (MusiQoL)

MusiQoL

Multiple Sclerosis International QoL questionnaire

You are invited to complete this questionnaire concerning different aspects of your life with MS. It is anticipated that this will help towards a better understanding of the real impact of your health problems.

Please answer the questions by ticking (☑) or checking (☒) the box that describes best your feelings **during the last 4 weeks**. Some questions relate to your private life; these are necessary to evaluate all aspects of your health. However, if you think that a question is not relevant to you, or if you do not want to answer a question, please move on to the next one.

Pr. Pascal Auquier, Dr Karine Baumstarck

Aix Marseille Université, France. Email: pascal.auquier@univ-amu.fr, karine.baumstarck@univ-amu.fr

Due to your MS, during the past 4 weeks, have you…

For each question, tick or check the response that is closest to your feelings	Never Not at all	Rarely A little	Sometimes Somewhat	Often A lot	Always Very much
had difficulty walking or moving outside?	☐	☐	☐	☐	☐
had difficulty with outdoor activities: e.g. shopping, going out to a movie…?	☐	☐	☐	☐	☐
had difficulty walking or moving around at home?	☐	☐	☐	☐	☐
been troubled by your balance or walking problems?	☐	☐	☐	☐	☐
had difficulty with leisure activities at home: e.g. do-it-yourself, gardening…?	☐	☐	☐	☐	☐
had difficulty with your occupational activities: e.g. integration, interruption, limitation…?	☐	☐	☐	☐	☐
been quickly tired?	☐	☐	☐	☐	☐
been short of energy?	☐	☐	☐	☐	☐
felt anxious?	☐	☐	☐	☐	☐
0 felt depressed or gloomy?	☐	☐	☐	☐	☐
1 felt like crying?	☐	☐	☐	☐	☐
2 felt nervous or irritated by a few things or situations?	☐	☐	☐	☐	☐

Due to your MS, during the past 4 weeks, have you…

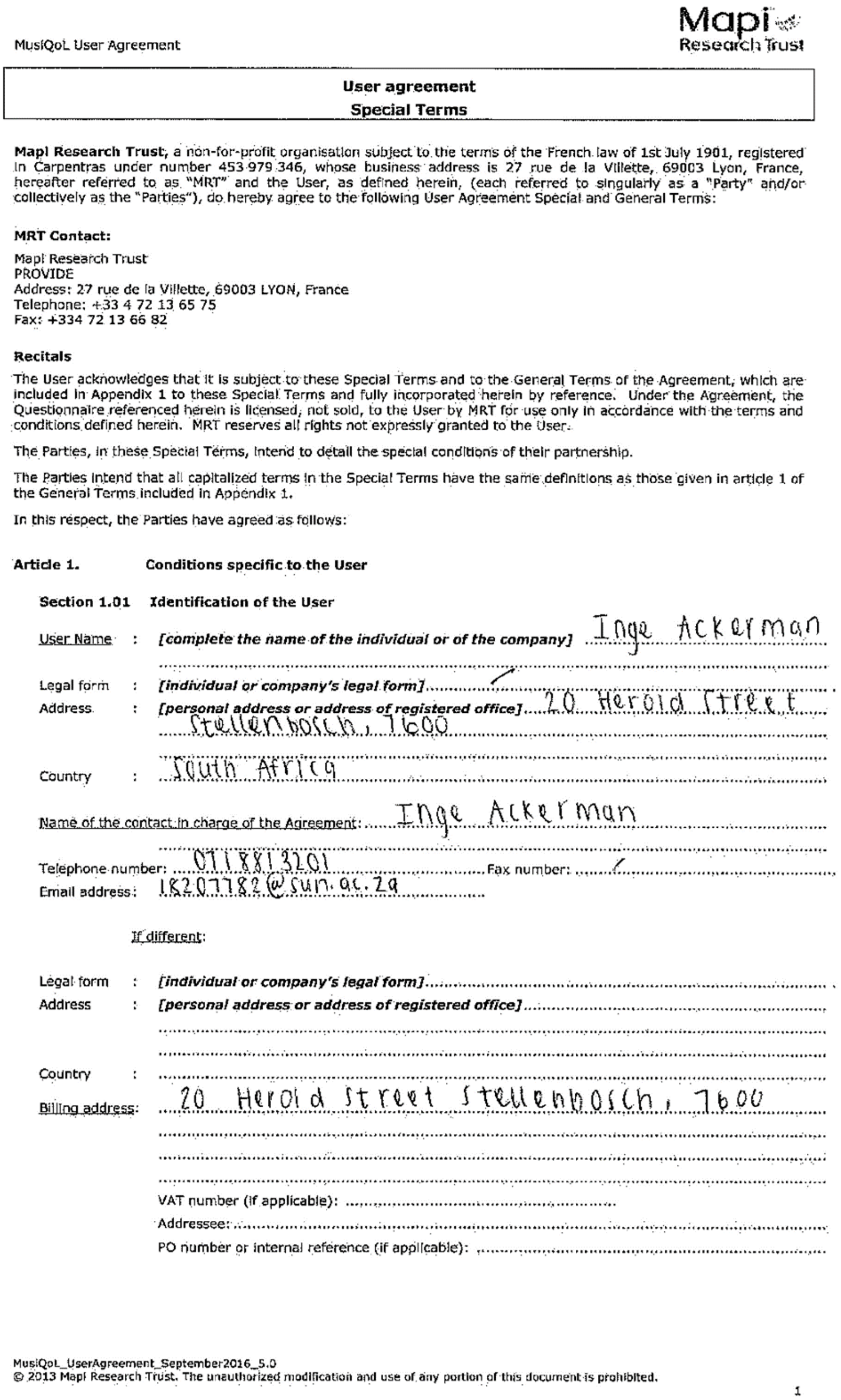
	For each question, tick or check the response that is closest to your feelings	Never Not at all	Rarely A little	Sometimes Somewhat	Often A lot	Always Very much
3	been troubled by loss of memory?	☐	☐	☐	☐	☐
4	had difficulty concentrating: e.g. when reading, watching a film, following a discussion…?	☐	☐	☐	☐	☐
5	been troubled by your vision: worsened or unpleasant?	☐	☐	☐	☐	☐
6	experienced unpleasant feelings: e.g. hot, cold…?	☐	☐	☐	☐	☐
7	talked with your friends?	☐	☐	☐	☐	☐
8	felt understood by your friends?	☐	☐	☐	☐	☐
9	felt encouraged by your friends?	☐	☐	☐	☐	☐
0	talked with your spouse/partner or your family?	☐	☐	☐	☐	☐
1	felt understood by your spouse/partner or your family?	☐	☐	☐	☐	☐
2	felt encouraged by your spouse/partner or your family?	☐	☐	☐	☐	☐

Due to your MS, during the past 4 weeks, have you…

	For each question, tick or check the response that is closest to your feelings	Never Not at all	Rarely A little	Sometimes Somewhat	Often A lot	Always Very much
3	felt satisfied with your love life?	☐	☐	☐	☐	☐
4	felt satisfied with your sex life?	☐	☐	☐	☐	☐
5	felt that your situation is unfair?	☐	☐	☐	☐	☐
6	felt bitter?	☐	☐	☐	☐	☐
7	been upset by the stares of other people?	☐	☐	☐	☐	☐
8	been embarrassed when in public?	☐	☐	☐	☐	☐
9	been satisfied with the information on your disease or the treatment given by the doctors, nurses, psychologists… taking care of your MS?	☐	☐	☐	☐	☐
0	felt understood by the doctors, nurses, psychologists… taking care of your MS?	☐	☐	☐	☐	☐
1	been satisfied with your treatments?	☐	☐	☐	☐	☐

Thank you very much for your participation

Appendix G: MusiQoL user agreement



User agreement
Special Terms

Mapi Research Trust, a non-for-profit organisation subject to the terms of the French law of 1st July 1901, registered in Carpentras under number 453 979 346, whose business address is 27 rue de la Villette, 69003 Lyon, France, hereafter referred to as "MRT" and the User, as defined herein, (each referred to singularly as a "Party" and/or collectively as the "Parties"), do hereby agree to the following User Agreement Special and General Terms:

MRT Contact:

Mapi Research Trust
PROVIDE
Address: 27 rue de la Villette, 69003 LYON, France
Telephone: +33 4 72 13 65 75
Fax: +334 72 13 66 82

Recitals

The User acknowledges that it is subject to these Special Terms and to the General Terms of the Agreement, which are included in Appendix 1 to these Special Terms and fully incorporated herein by reference. Under the Agreement, the Questionnaire referenced herein is licensed, not sold, to the User by MRT for use only in accordance with the terms and conditions defined herein. MRT reserves all rights not expressly granted to the User.

The Parties, in these Special Terms, intend to detail the special conditions of their partnership.

The Parties intend that all capitalized terms in the Special Terms have the same definitions as those given in article 1 of the General Terms included in Appendix 1.

In this respect, the Parties have agreed as follows:

Article 1. Conditions specific to the User

Section 1.01 Identification of the User

User Name : *[complete the name of the individual or of the company]* Inge Ackerman
Legal form : *[individual or company's legal form]*
Address : *[personal address or address of registered office]* 20 Herold Street
Stellenbosch, 7600
Country : South Africa

Name of the contact in charge of the Agreement: Inge Ackerman
Telephone number: 0718813201 Fax number:
Email address: 18207782@sun.ac.za

If different:

Legal form : *[individual or company's legal form]*
Address : *[personal address or address of registered office]*
Country :
Billing address: 20 Herold Street Stellenbosch, 7600
VAT number (if applicable):
Addressee:
PO number or internal reference (if applicable):

Section 1.02 Identification of the Questionnaire

Title of the Questionnaire: MusiQoL (Multiple Sclerosis International Quality Of Life Questionnaire)

Author: Pascal Auquier, Marie-Claude Simeoni and Karine Baumstark

Owner: Pascal Auquier and Karine Baumstark

Copyright notice: © MusiQoL 2008

References: Simeoni M, Auquier P, Fernandez O et al. Validation of the Multiple Sclerosis International Quality of Life questionnaire. Mult Scler. 2008 Mar;14(2):219-30. Epub 2007 Oct 17.

Article 2. Rights to use

Section 2.01 Context of the Use of the Questionnaire

The User undertakes to only use the Questionnaire in the context of the Study as defined hereafter.

[Tick the box and complete the corresponding fields]

☐ *individual clinical practice (please go directly to section 2,02)*

Planned term of use: ....

Number of patients expected: ....

☐ *clinical project or study*

Title: ....

Study/protocol reference: ....

Disease or condition: ....

Type of research: ☐ clinical trial : ☐Phase II / ☐Phase III
☐ epidemiologic/observational
☐ other: ....

Questionnaire used as primary end point: ☐ yes
☐ no

Number of patients expected: ....

Number of submissions to the Questionnaire for each patient: ....

Term of clinical follow-up for each patient: ....

Planned term for project: start (month/year): ....
end (month/year): ....

Mode of Administration: ☐ paper
☑ electronic

If electronic administration, please indicate mode of data collection:
☐ Hand held device – specify device: ....
☐ Interactive Voice Response (IVR) – specify: ....
☑ Web - specify website: sunsurveys through Face book

☐ Digital Pen - specify device: ....

☐ Tablet - specify device: ....

☑ other - specify: Filled in by hand.

Use of e-vendor:

☐ no

☑ yes - name: Sunsurveys.

☑ *other project*

Title: Coping styles and quality of life in MS patients.

Disease or condition: patients with multiple sclerosis (MS)

Planned term of use: start (month/year): 2018
end (month/year): 2019

Description of the project: This project will examine the relationship between coping styles and quality of life in individuals with multiple sclerosis

Presentation format of project: Thesis (paper)

Financing of the Project:

☑ Not funded academic research/project, individual medical practice	*Projects not explicitly funded, but funding comes from overall departmental funds or from the University or individual funds.*
☐ Funded academic research/project	*Projects receiving funding from commerce, government, EU or registered charity. **Funded academic research– sponsored by industry- fits the "commercial study/project" category.***
☐ Commercial study/project	*Industry, CRO, any for-profit companies*
Grants / Sponsoring from (if any) *(name of the governmental/ foundation/company or other funding/sponsoring source):*	....

Section 2.02 Conditions for use

The User undertakes to use the Questionnaire in accordance with the conditions for use defined hereafter.

(a) Rights transferred

Acting in the Owner's name, MRT transfers the following limited, non-exclusive rights, to the User (the "Limited Rights")

(i) to use the Questionnaire, only as part of the Study; this right is made up exclusively of the right to communicate it to the Beneficiaries only, by any means of communication and by any means of remote distribution known or unknown to date, subject to respecting the conditions for use described hereafter; and

(ii) to reproduce the Questionnaire, only as part of the Study; this right is made up exclusively of the right to physically establish the Questionnaire or to have it physically established, on any paper, electronic, analog or digital medium, and in particular documents, articles, studies, observations, publications, websites whether or not protected by restricted access, CD, DVD, CD-ROM, hard disk, USB flash drive, for the Beneficiaries only and subject to respecting the conditions for use described hereafter; and

(ii) Should the Questionnaire not already have been translated into the language requested, the User is entitled to translate the Questionnaire or have it translated in this language, subject to informing MRT of the same beforehand by the signature of a Translation Agreement indicating the terms of it and to providing a copy of the translation thus obtained as soon as possible to MRT.

(iii) In the context of commercial studies or any project funded by the pharmaceutical industry, the User undertakes to have the Questionnaire translated in this language by Mapi Language Services; Mapi Language Services is the only organization authorized by the Owner to perform linguistic validation/translation work on the Questionnaire.

The User acknowledges and accepts that it is not entitled to amend, modify, condense, adapt, reorganise the Questionnaire on any medium whatsoever, in any way whatsoever, even minor, without MRT's prior specific written consent.

(b) Specific conditions for the Questionnaire

- Use in Individual clinical practice or Research study / project

User shall:

- Cite the reference publications
- never duplicate, transfer or publish the Questionnaire without indicating the Copyright Notice
- Insert the Owner's copyright notice on all pages/screens on which the Questionnaire will be presented
- Mention the following information: "The MusiQoL contact information and permission to use: Mapi Research Trust, Lyon, France. Internet: https://eprovide.mapi-trust.org "
- In case of use of an IT Company (e-vendor), User shall check with Mapi Research Trust that the IT Company has signed the necessary License Agreement with Mapi Research Trust before developing the electronic version of the Questionnaire

In the case of use of an electronic version of the Questionnaire in academic studies, the User undertakes to respect the following special obligations:

- Submit the screenshots of all the Pages where the Questionnaire appears to Mapi Research Trust before release for approval and to check that the above-mentioned requirements have been respected.

In the case of use of an electronic version of the Questionnaire in commercial studies / projects, the User undertakes to respect the following special obligations:

- For the first migration of the Questionnaire (generally the original version) into a specific electronic device
  - o Review of screenshots:

  After implementation of the Questionnaire into the device, the user and/or IT Company will generate screen captures (screenshots) of the original questionnaire as displayed in the device. These will be reviewed by Mapi to check that they are consistent with the original paper version in terms of presentation, content and completion except for specific instructions related to the electronic administration. Corrections that may be needed will be reported to the user and/or IT Company. In this case, screenshots after correction will be generated for another round of review by Mapi until all screenshots are approved.

  - o Usability testing:

  Usability testing is a methodology which aims to examine whether respondents are able to use a device and associated software as intended. Major issues of concern in usability testing typically include device complexity, navigation and response selection for example.
  The objective of this investigation is to ensure that the electronic version of the questionnaire as included in the device meets usability criteria, focusing on functional aspects and respondents' understanding of instructions. Usability testing consists in interviews with patients where patients will complete the electronic version of the Questionnaire on the device and comment on their understanding of the instructions, ease of use and handiness of the device. A Usability testing report presenting results will be produced. If any changes are recommended, these will be implemented by the user and/or IT Company. If issues raised by respondents are rated as major, the user and/or IT Company may need to perform additional developments and another round of interviews may be needed.

  The review of screenshots is mandatory. The usability testing is highly recommended by Mapi, however should the User and/or IT Company decide not to perform this step, Mapi Research Trust shall not be held responsible for any consequence and expense associated with this decision which shall remain the User and/or IT Company's sole liability.

  The review of screenshots and usability testing, when and if performed, shall be performed exclusively by Mapi and shall be sponsored by the User.

  The performance of the review of screenshots and usability testing will result in a certification of the electronic device original version of the Questionnaires by Mapi for future licenses.
- For the migration of other language versions of the Questionnaire on an existing certified specific electronic device.

- Update version

After the electronic device original version of the Questionnaire is fully ready, the Questionnaire's language versions developed for paper administration will be updated to reflect the changes in wording of instructions implemented in the electronic device original version of the questionnaire.
Native speakers of the languages will reflect the changes made to the electronic device original version of the Questionnaire and will provide English equivalents of all changes made for Mapi's quality control.

- Review of screenshots:

After implementation of the Questionnaire into the device, the user and/or IT Company will generate screen captures (screenshots) of the original questionnaire as displayed in the device. These will be reviewed by Mapi to check that they are consistent with the original paper version in terms of presentation, content and completion except for specific instructions related to the electronic administration. Corrections that may be needed will be reported to the user and/or IT Company. In this case, screenshots after correction will be generated for another round of review by Mapi until all screenshots are approved.

The update of version and review of screenshots are mandatory. These steps shall be performed exclusively by Mapi and shall be sponsored by the User.

- The performance of the update of version and review of screenshots will result in a certification of the electronic device language version of the Questionnaires by Mapi for future licenses.

- Use in a publication or on a website with unrestricted access:

In the case of a publication, article, study or observation on paper or electronic format of the Questionnaire, the User undertakes to respect the following special obligations:

- not to include any full copy of the Questionnaire, but a protected version with the indication "sample copy, do not use without permission"
- to indicate the name and copyright notice of the Owner
- to include the reference publications of the Questionnaire
- to indicate the details of MRT for any information on the Questionnaire as follows: contact information and permission to use: Mapi Research Trust, Lyon, France– Internet: https://eprovide.mapi-trust.org or karine.baumstarck@univ-amu.fr or pascal.auquier@univmed.fr
- to provide MRT, as soon as possible, with a copy of any publication regarding the Questionnaire, for information purposes
- to submit the screenshots of all the Pages where the Questionnaire appears to MRT before release to check that the above-mentioned requirements have been respected.

- Use for dissemination:

  - On a website with restricted access:

In the case of publication on a website with restricted access, the User may include a clean version of the Questionnaire, subject to this version being protected by a sufficiently secure access to only allow the Beneficiaries to access it.
The User undertakes to also respect the following special obligations:

- to indicate the name and copyright notice of the Owner
- to include the reference publications of the Questionnaire
- to indicate the details of MRT for any information on the Questionnaire as follows: contact information and permission to use: Mapi Research Trust, Lyon, France – Internet: https://eprovide.mapi-trust.org or karine.baumstarck@univ-amu.fr or pascal.auquier@univmed.fr
- to submit the screenshots of all the Pages where the Questionnaire appears to MRT before release to check that the above-mentioned requirements have been respected.

  - On promotional / marketing documents

In the case of publication on promotional/marketing documents, the User undertakes to respect the following special obligations:

- to indicate the name and copyright notice of the Owner
- to include the reference publications of the Questionnaire
- to indicate the details of MRT for any information on the Questionnaire as follows: contact information and permission to use: Mapi Research Trust, Lyon, France.– Internet: https://eprovide.mapi-trust.org
- to provide MRT, as soon as possible, with a copy of any publication regarding the Questionnaire, for information purposes
- to submit the screenshots of all the Pages where the Questionnaire appears to MRT before release to check that the above-mentioned requirements have been respected.

For any other use not defined herein, please contact MRT for the specific conditions of use and access fees (if applicable).

Article 3. Term

MRT transfers the Limited Rights to use the Questionnaire as from the date of delivery of the Questionnaire to the User and for the whole period of the Study.

Appendix 1 to the Special Terms:
User Agreement General Terms

User has read and accepted the MRT's General Terms of the Agreement, which are available on MRT's website:
https://eprovide.mapi-trust.org/user-agreement-general-terms