Exploring Fatigue amongst People Living with Multiple Sclerosis in the Western Cape

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Declaration

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Summary

Rationale and Aim

Multiple sclerosis fatigue (MS-F) is a distressing and disabling symptom of multiple sclerosis (MS) that is commonly experienced by people with multiple sclerosis (PwMS). Whilst a substantial body of knowledge exists on MS-F, phenomenological insight into the significance of MS-F within PwMS's lives is sparce – both globally and nationally. Consequently, the present study sought to explore the lived experiences of MS-F amongst MS-F sufferers in the Western Cape (WC). To this effect, the present study aimed to identify and clarify how PwMS in the WC understood MS-F as a feature of life (FOL). This includes how PwMS in the WC perceived and made sense of: (a) MS-F as a symptomatic experience, (b) MS-F impacts on daily life, (c) MS-F management, and (d) coping with MS-F.

Worldview and Theoretical Orientation

The present study assumed a constructivist worldview. As such, this study ascribed to a relativist ontology as well as a transactional and subjectivist epistemology. Furthermore, interpretative phenomenological analysis (IPA) was adopted as a theoretical orientation to guide the research. Here IPA guided the research through its theoretical foundations of phenomenology, hermeneutics, and ideography.

Research Design and Methodology

To elucidate lived experiences, an exploratory and cross-sectional research design was employed. Through purposive sampling, 12 MS-F sufferers living in the WC were recruited according to specific inclusion/exclusion criteria. These participants completed a biographical questionnaire, the Patient-determined Disease Steps (PDDS), and the Chalder Fatigue Scale (CFQ) for descriptive purposes. Additionally, they also participated in individual semi-structured telephonic interviews to collect experiential accounts of living with MS-F. These interviews were audio recorded and transcribed. Hereafter, I selected the six most data rich and sophisticated accounts for subsequent IPA analyses.

Results

The present study identified four understandings (i.e. superordinate themes) as characterising participants' lived experiences of MS-F. Participants understood MS-F as a symptom through its symptomatic features. Here participants perceived MS-F as a lack of energy, an ever-present inconsistency of life, and a subjective mind-body phenomenon. Furthermore, participants understood MS-F as restricting their capacity to participate in the world. This understanding comprised notions of a restricted functional capacity and losses of both independence and spontaneity. MS-F management was understood as the planned accommodation of MS-F through energy maintenance. Here MS-F management was perceived as preparatory in nature whilst energy maintenance signified a route to realising MS-F management. Lastly, participants understood coping with MS-F as the acceptance of the fatigued self and a fatigued life. Here, coping involved an acceptance of MS-F and its restrictions on life as well as an acceptance of MS-F as a FOL.

Conclusion

MS-F is a meaning-laden phenomenon. It is a symptom with a considerable intrapersonal presence and has substantial implications and consequences for life. Here the present study provides a more person-centred insight into the significance of MS-F within PwMS's lives. These findings may prove valuable to existing theory as well as to those working with MS-F sufferers.

Key words: multiple sclerosis, multiple sclerosis fatigue, multiple sclerosis-related fatigue, fatigue, lived experience, interpretative phenomenological analysis

Opsomming

Rasionaal en Doelwit

Veelvuldige sklerose moegheid (VS-M) is ’n angswekkende en benadelende simptoom van veelvoudige sklerose wat algemeen onder mense met veelvuldige sklerose (MmVS) voorkom. Alhoewel daar aansienlike kennis rakende VS-M bestaan, is fenomenologiese insig tot die lewenservarings van MmVS skaars – beide globaal en nasionaal. Gevolglik is die doel van die huidige studie om die lewenservarings van VS-M onder Wes-Kapenaars met VS te ondersoek. Tot hierdie effek, het die huidige studie beoog om uit te vind hoe MmVS in die Wes-Kaap VS-M as ʼn aspek van hul lewens verstaan. Dit het ingesluit hoe MmVS in die Wes-Kaap waargeneem en sin gemaak het van: (a) VS-M as ʼn simptomatiese ervaring, (b) VS-M se impakte op alledaagse lewe, (c) VS-M bestuur, asook (d) VS-M hantering.

Wêreldbeeld en Teoretiese Oriëntasie

Die huidige studie is vanuit ʼn konstruktivistiese paradigma onderneem. As sulks, was ’n relatiwistiese ontologie sowel as ʼn transaksionele en subjektiewe epistemologiese posisie beklee. Vervolgens is interpretatiewe fenomenologiese analise as a teoretiese raamwerk gebruik om die navorsing te lei. Hier was navorsing deur IPA se teoretiese grondbeginsels van fenomenologie, hermeneutiek en ideografie gelei.

Navorsingsontwerp en Navorsingsmetode

ʼn Verkennende deursnitstudie-navorsingsontwerp was toegepas om lewenservarings te ondersoek. Deur middel van doelgerigte steekproefneming was 12 VS-M lyers in die Wes-Kaap volgens spesifieke insluitingskriteria/uitsluitingskriteria gewerf. Hierdie deelnemers het ʼn biografiese vraelys, die “Patient-determined Disease Steps”, en die “Chalder Fatigue Scale” vir beskrywende doeleindes voltooi. Hulle het ook deelgeneem aan individuele, semi-gestruktureerde telefoniese onderhoude om ervaringsvolle beskrywings van lewe met VS-M in te samel. Onderhoude was met behulp van oudio-opnames opgeneem en getranskribeer. Daarna het ek die ses mees dataryke en gesofistikeerde beskrywings vir opvolgende IPA analise gekies.

Navorsingsresultate

Die huidige studie het vier begrippe geïdentifiseer wat deelnemers se lewenservarings van VS-M karakteriseer. Deelnemers het VS-M duer middel van VS-M se simptomatiese kenmerke as ʼn simptoom verstaan. Hier het deelnemers VS-M as ʼn afwesigheid van energie, ʼn ewig teenwoordige inkonsekwentheid, en ʼn subjektiewe verstand-liggaam verskynsel waargeneem. Verder het deelnemers waargeneem dat VS-M beperkend was tot hul kapasiteit om aan die wêreld deel te neem. Hierdie begrip het persepsies van beperkte funksionele kapasiteit en verliese aan onafhanklikheid en spontaniteit ingesluit. VS-M bestuur is verstaan as die beplande akkommodering van VS-M deur energiehandhawing. Hier was VS-M bestuur as voorbereidend van aard waargeneem, terwyl energiehandhawing ʼn weg na die bestuur van VS-M aangedui het. Laastens het deelnemers die hantering van VS-M verstaan as die aanvaarding van ʼn moeë self en ʼn moeë lewe. Hier het hantering ʼn aanvaarding van VS-M en verwante gevolge, asook die aanvaarding van VS-M as deel van die lewe behels.

Gevolgtrekking

VS-M is ʼn betekenisvolle verskynsel. Dit is ʼn simptoom met ʼn omvangryke intrapersoonlike teenwoordigheid wat aansienlike implikasies en gevolge vir die lewe het. Die huidige studie bied ʼn meer mens-gesentreerde insig tot die betekenis van VS-M vir MmVS se lewens. Hierdie bevindings kan ʼn waardevolle bydrae tot bestaande teorie sowel as vir diegene wat met VS-M lyers werk, lewer.

Sleutelwoorde: veelvuldige sklerose, veelvuldige sklerose moegheid, veelvuldige sklerose verwante moegheid, lewenservarings, interpretatiewe fenomenologiese analise

"… my fatigue and exhaustion consume me. It does weigh me down from the centre of my being. The only thing I can think to relate it to is, it's like I'm sinking in quicksand. The weight of it is pulling me down, and some days it's all I can do to keep my head from going under. Every attempt to function properly is altered by the heaviness. Every move and every thought take effort and the little bit of strength that I have left."

Wyatt (2018) on the meaning of MS-F.

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List of Abbreviations

Conceptual Abbreviations

CFQ:	Chalder Fatigue Scale
CNS:	Central nervous system
FI:	Fatigue intensity
FOL:	Feature of life
HCP:	Health care professional
HIV:	Human immunodeficiency virus
IBD:	Inflammatory bowel disease
IPA:	Interpretative phenomenological analysis
ME:	Myalgic encephalomyelitis
MND:	Motor neuron disease
MS:	Multiple sclerosis
MS-F:	Multiple sclerosis fatigue
PDDS:	Patient-determined Disease Steps
PPMS:	Primary progressive multiple sclerosis
PRMS:	Progressive relapsing multiple sclerosis
PwMS:	People with multiple sclerosis
PwoCCs:	People with other chronic conditions
QOL:	Quality of life
RA:	Rheumatoid arthritis
RRMS:	Relapsing-remitting multiple sclerosis
SPMS:	Secondary progressive multiple sclerosis

Geographic Abbreviations

NZ:	New Zealand
SA:	South Africa
UK:	United Kingdom
USA:	United States of America
WC:	Western Cape (i.e., a province within South Africa)

Institutional Abbreviations

APA:	American Psychological Association
HREC:	Health Research Ethics Committee of Stellenbosch University
MSC:	Multiple Sclerosis Council for Clinical Practice Guidelines
MSIF:	Multiple Sclerosis International Federation
MSSA:	Multiple Sclerosis South Africa
NARCOMS:	North American Research Committee on Multiple Sclerosis
WCPC:	Welgevallen Community Psychology Clinic

Linguistic Abbreviations

e.g.:	exempli gratia (for example)
i.e.:	id est (that is)

Methodological Abbreviations

n:	Number of cases in a subsample
N:	Total number of cases in the sample
RQ:	Research question
α:	Cronbach alpha

Key Terms

Coping:	In accordance with the American Psychological Association (APA) (2020), coping refers to “the use of cognitive and behavioral strategies to manage the demands of a situation when these (i.e., the demands) are appraised as taxing, or exceeding one’s resources, or to reduce the negative emotions and conflict caused by stress.” (Coping, para. 1).
Daily Life:	Daily life refers to that which is “happening, done, or produced everyday” (Oxford University Press, 2021a, para 1). For all intents and purposes “daily life” is synonymous with “everyday life”.
Everyday Life:	Everyday life may be defined as that which is “used or happening every day or regularly” (Oxford University Press, 2021b, para 1) and refers to the commonplace and ordinary aspects of life (Lexico, 2021b). For all intents and purposes “everyday life” is synonymous with “daily life”.
Experiences:	In accordance with Dilthey (1976) and Smith et al. (2009/2012d), experiences refer to those everyday phenomena which people are continually and unselfconsciously caught up in. See section 3.3 for further insight into “experience” as a concept.
Hermeneutics:	Hermeneutics refers to the theory of interpretation and is a theoretical foundation of interpretative phenomenological analysis. Hermeneutics designates phenomenological ventures to be hermeneutic endeavours (Smith et al., 2009/2012a) by holding that meanings can only be accessed through interpretation (Biggerstaff & Thompson, 2008). See section 3.2.2 for further details on hermeneutics.

Ideography:	Ideography is a theoretical foundation of interpretative phenomenological analysis that is concerned with how specific individuals understand phenomena within their specific context. Here ideography holds that insight into the idiosyncratic understandings of phenomena provides insight into the more universal understandings of phenomena (Smith et al., 2009/2012a). See section 3.2.3 for further details on ideography.
Interpretivism:	See hermeneutics.
Lived experiences:	In accordance with Dilthey (1976) and Smith et al. (2009/2012d), lived experiences refer to those more comprehensive experiences of phenomena linked by a shared meaning. See section 3.3 for further details on “lived experience” as a concept.
Management:	In neurological terms, management may be defined as centring around disease-controlling strategies and healthy lifestyle behaviours. Here disease-controlling strategies refer to strategies that control symptoms, limit complications and curtail disease progression, whereas healthy lifestyle behaviours refer to behaviours that enhance health and reduce the risk for lifestyle attributable illness (Audulv et al., 2016).
Multiple Sclerosis:	Multiple sclerosis is a neurodegenerative disease that affects the central nervous system (Ayache & Chalah, 2017; Yang et al., 2017)

Multiple Sclerosis Fatigue:	Whilst there is no consensus surrounding a definition of fatigue as a symptom of multiple sclerosis (Ayache & Chalah, 2017; Induruwa et al., 2012), this type of fatigue is commonly defined as “a subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activities” (MSC, 1998, pp. 2). See section 2.1 for a review of how fatigue in multiple sclerosis has been defined.
Participant:	This refers to those people who met inclusion criteria and were recruited into the final sample.
Phenomenology:	Phenomenology is a theoretical foundation of interpretative phenomenological analysis (Smith et al., 2009/2012a) concerned with how people understand salient phenomena (Smith et al., 2009/2012d) within their consciousness (Smith et al., 2009/2012a). See section 3.2.1 for further details on phenomenology.
Prospective participant:	This refers to those people interested in participating in this research study prior to recruiting the final sample.

Chapter 1: Introduction

MS is a debilitating and lifelong neurodegenerative disease that is characterised by axonal demyelisation and neuronal degeneration of the central nervous system (CNS) (Ayache & Chalah, 2017; Yang et al., 2017). The most recent estimates of the Multiple Sclerosis International Federation (MSIF) (2013) suggest that MS affects around 2.3 million people worldwide (i.e. 33 per 100,000 individuals). Existing epidemiological data on MS amongst South Africans has highlighted South Africa (SA) as a medium MS frequency zone (Modi et al., 2008), according to Kurtzke's (2000) geographical classification system. However, more contemporary estimates indicate that there are around 32 MS cases per 100,000 South African citizens (CBC News, 2018) which designates SA as a high MS frequency zone (i.e. more than 30 cases per 100,000 individuals) (Kurtzke, 2000). These statistics suggest that the prevalence of MS is on the rise in SA. Nonetheless, it is unclear whether this prevalence increase is attributable to an increased incidence of MS or advancements in health care professionals' (HCP) diagnostic capabilities.

Whilst research has made progress in elucidating MS's complex aetiology (Dobson & Giovannoni, 2019), MS's development remains poorly understood (Dennison et al., 2009; Sadock et al., 2015). Nevertheless, MS's development seems to involve a combination of both genetic and environmental factors (Ascherio, 2013; Courtney et al., 2009; Dobson & Giovannoni, 2019). Although MS may develop at any age, it typically has its onset during early adulthood (MSIF, 2013) between the ages of 20 and 40 years (Modi et al., 2008; Sadock, et al., 2015). Furthermore, MS disproportionately affects women through a female-to-male frequency ratio of 2:1 (Alonso & Hernán, 2008; MSIF, 2013; Reipert, 2004). As such, MS affects young and middle-aged adults (particularly women) at the height of their physical and economic potential (Stuifbergen & Rogers, 1997). Taken together, MS's early adulthood onset and greater prevalence amongst South Africans highlights MS as a significant public health concern worth researching. This need to investigate MS-related topics within the SA context is further compounded by the fact that MS is a debilitating, rarely fatal, and currently incurable lifelong disease (Beiske et al., 2008; Dennison et al., 2009) that has not been extensively researched in South Africa.

Throughout its debilitating and rarely fatal lifelong course, MS follows an unpredictable and idiosyncratic course (Beiske et al., 2008; Dennison et al., 2009) characterised by the progressive accumulation of neurological deficits (Ayache & Chalah, 2017). In this regard, MS subtypes have been identified as reflective of the broader clinical courses MS may follow, namely: (a) relapsing-remitting MS (RRMS), (b) primary progressive MS (PPMS), (c) secondary progressive MS (SPMS), and (d) progressive relapsing MS (PRMS) (Courtney et al., 2009). Nevertheless, and regardless of the subtype, progressive neurodegeneration inevitably results in the accumulation of neurological signs and symptoms (Compston & Coles, 2008; Lezak et al., 2012).

As a neurological condition, the clinical presentation of MS may be characterised by an array of disabling physical symptoms and neuropsychological deficits (i.e. emotional disturbances and cognitive impairments) (Brenner et al., 2018; Dennison et al., 2009). These symptoms and deficits may differ dramatically according to variations in MS lesions (i.e. neural damage) (Halper, 2007; Lezak et al., 2012) but may include altered motor functioning (e.g. paralysis), cognitive impairment, bladder and bowl dysfunction, visual impairments (e.g. blurred vision) and a loss/alteration of sensations (e.g. paraesthesia/numbness) (Induruwa et al., 2012). Amidst such symptoms, MS fatigue (MS-F) is one of the most common and frequently experienced MS-related symptoms (Debouverie et al., 2008; Lerdal et al., 2007; Yang et al., 2017). More than 80% of MS patients identify MS-F to be a current symptom (Lezack et al. 2012) with 75% - 90% of MS patients reporting MS-F experiences at some point in time (Bisecco et al., 2016; Fisk et al., 1994; Lerdal et al., 2007). Moreover, PwMS frequently self-report fatigue as one of the most distressing and disabling MS-related symptoms that they experience (Ayache & Chalah, 2017; Aygünoğlu et al., 2015; Lezak et al., 2012).

MS-F has a complex aetiology which is neither fully elucidated nor wholly understood (Ayache & Chalah, 2017; Kos et al., 2004) and MS-F may develop at any point in MS's progression (Comi et al., 2001; Kos et al., 2004). MS-F represents a complex, multi-dimensional, and multi-causal symptom that is subjectively experienced by PwMS (Induruwa et al., 2012). As such, it is unsurprising that there is no agreed upon definition of MS-F (Ayache & Chalah, 2017) and that MS-F has been described in various ways in research (Chaudhuri & Behan, 2004; Leocani et al., 2008; Lerdal et al., 2007; Mills & Young, 2008). As a symptom, MS-F differs from "normative" fatigue as experienced by healthy individuals (Fisk et al., 1994) and the fatigue experienced in other conditions (Krupp et al., 2010). It is frequently described as an invisible symptom that is not easily apparent to others (Johnson et al., 2004; Jongbloed, 1998; Stuifbergen & Rogers, 1997) and may be experienced on a daily basis (Krupp et al., 2010; Mills & Young, 2008).

PwMS have reported that MS-F has a substantial impact on their everyday lives (Olsson et al., 2005). Here it appears that MS-F detrimentally impacts the biopsychosocial aspects of PwMS's lives (Flensner et al., 2003; García Jalón et al., 2013; Newton et al., 2020). In this respect, MS-F has been found to restrict and limit PwMS's personal lives, social lives (Barak & Achiron, 2006; Malcomson et al., 2008), family lives (Barak & Achiron, 2006; Johnson et al., 2004), and occupational lives (Barak & Achiron, 2006; Johnson et al., 2004; Jongbloed, 1998; Malcomson et al., 2008). Considering these impacts, it is unsurprising that MS-F adversely affects quality of life (QOL) (Barak & Achiron, 2006; Krupp et al., 2010).

1.1 Problem Statement and Research Rationale

There is a growing academic and clinical interest in MS-F as a symptom, and a substantial body of literature exists on MS-F. Nonetheless, these inquiries have largely been quantitative in nature and concerned with: (a) elucidating MS-F's aetiological basis (Akcali et al., 2017; Bisecco et al., 2016; Heesen et al., 2006), (b) determining how MS-F correlates and relates to other variables, [e.g. disease features, other MS-symptoms (Biberacher et al., 2018; Aygünoğlu et al., 2015; Koch et al., 2009; Téllez et al., 2006) or QOL (Fernández-Muñoz et al., 2015; Pittion-Vouyovitch et al., 2006)], (c) developing and assessing psychometric measures of MS-F (Amtmann et al., 2012; Chilcot et al., 2016; Rietberg et al., 2010), and (d) developing/assessing interventions for MS-F

(Herden & Weissert, 2020; Matuska et al., 2007; Moss-Morris et al., 2012; van den Akker et al., 2016, 2017). By comparison, there is a paucity of research exploring how PwMS understand, conceptualise, and describe MS-F. At the time of this writing, there exists only a handful of qualitative studies that have examined MS-F from PwMS's perspective (Blaney & Lowe-Strong, 2009; Gagliardi, 2003; Johnson et al., 2004; Kayes et al., 2011; Mills & Young, 2008; Moriya & Kutsumi, 2010; Olsson et al., 2005; Smith et al., 2015; Stuifbergen & Rogers, 1997; Turpin et al., 2017). Whilst some of these studies generated findings on how PwMS conceptualise their experience of MS-F; only a small minority of studies have explicitly sought to elucidate PwMS's lived experiences of MS-F (Flensner et al., 2003; Johnson et al., 2004; Olsson et al., 2005; Turpin et al., 2017). Furthermore, as far as I could tell from my review of the literature, nearly all qualitative studies on MS-F were conducted within high income countries such as the United States of America (USA) (Gagliardi, 2003; Johnson et al., 2004; Stuifbergen & Rogers, 1997), the United Kingdom (UK) (Blaney & Lowe-Strong, 2009; Mills & Young, 2008), Germany (Coenen et al., 2011), Sweden (Flensner et al., 2003; Olsson et al., 2005), New Zealand (NZ) (Kayes et al., 2011; Smith et al., 2015), Australia (Turpin et al., 2017), and Japan (Moriya & Kutsumi, 2010).

Whilst numerous researchers have investigated MS-F through statistical means; only a handful of studies have explored how PwMS understand MS-F as a FOL. Moreover, at the time of this writing, African and South African accounts of living with MS-F have not been explored. The present study aims to address these gaps in existing literature by exploring Western Capetonian MS-F sufferers' lived experiences of MS-F (i.e. how they understand MS-F as a FOL). It is hoped that this exploration may: (a) address the relative lack of a more person-centred understanding of MS-F in existing literature, and (b) document how MS-F sufferers in a SA context understand MS-F.

1.2 Research Question

Given the gaps in contemporary literature on how PwMS understand MS-F as a FOL, I sought to answer the following research question (RQ): "What are the perceptions and meanings of living with MS-F amongst PwMS in the Western Cape (WC)?" I attempted to answer this RQ by exploring participants' lived experiences of MS-F, something which involved attaining a specific research aim and set of objectives.

1.3 Research Aim and Objectives

In direct alignment with my RQ, the primary aim of this study was: "To explore how PwMS in the WC perceive and make sense of living with MS-F". To achieve this aim, I focused on attaining four more specific objectives. These objectives were:

1. To explore and interpret accounts of MS-F as a symptomatic experience.
2. To explore and interpret accounts of how MS-F impacts daily life.
3. To explore and interpret accounts of how PwMS manage MS-F.
4. To explore and interpret accounts of how PwMS cope with MS-F.

As illustrated, I sought to explore PwMS's lived experiences of fatigue by focusing on and achieving the above listed objectives. Here each of the objectives was geared at elucidating how PwMS understood MS-F in relation to specific aspects of their lived worlds. These objectives were central considerations in my research design and methodology.

1.4 Overview of Paradigmatic Stances and Theoretical Orientation

To explore PwMS's lived experiences of MS-F in the WC, I adopted a constructivist worldview in accordance with Guba and Lincoln (1994). As such, I ascribed to a notion of ontological relativism and espoused a transactional and subjectivist epistemological stance. By adopting a constructivist worldview, I regarded PwMS's understandings/perceptions of MS-F as subjective social constructions which could only be explored in interaction with MS-F sufferers. Concurrently, I used IPA as a theoretical orientation to guide me in exploring PwMS's lived experiences of MS-F in the WC. Here IPA's theoretical foundations [i.e. phenomenology, hermeneutics, and ideography (Smith et al., 2009/2012a)] informed my research design and methodology, whilst also providing a guide for the exploration of lived experiences. The use of IPA was appropriate, since IPA is concerned with examining lived experiences (Smith & Osborn, 2015) as perceived within the consciousness (Smith et al., 2009/2012a). Moreover, IPA is well suited for examining how individuals understand complex and ambiguous research topics (Smith & Osborn, 2015) such as MS-F.

1.5 Thesis Layout

This thesis consists of six chapters. I provide a succinct overview of what to anticipate and expect from each of these chapters below.

In Chapter 1 (i.e. the current chapter), I provided some background information on MS-F and highlighted this study's RQ, aim, and objectives. Additionally, this chapter illustrated the need for exploring the lived experiences of MS-F amongst MS-F sufferers in the WC.

In Chapter 2, I review literature relevant to the present study. This review includes a review of MS-F's definition, MS-F as a clinical entity, MS-F's aetiology, and MS-F's clinical features. Furthermore, I also review literature on how PwMS may understand: (a) MS-F as a symptom, (b) MS-F's impacts on daily life, (c) MS-F management, and (d) coping with MS-F.

Within Chapter 3, I delineate the paradigmatic stance I adopted in conducting this research study. Moreover, I highlight and discuss IPA's philosophical cornerstones as my theoretical orientation. I also describe how I translated these philosophies into tangible research practice. Lastly, I discuss and differentiate between what constitutes an "experience" and "lived experience" within the context of the present study.

In Chapter 4, I provide a detailed account of the research design and methodologies I employed in this study. I start the chapter by highlighting the characteristic features of my research design. Thereafter, I elaborate on the sampling strategy and procedure I used to recruit participants. Following this, I present and describe the data collection tools used, and data collection procedure enacted, in this study. Thereafter, I detail the data analytic procedure and strategy I used to explore participants' lived experiences of MS-F. Subsequently, I present my approach to reflexivity and bracketing, whereafter I detail the ethical considerations of this study. Lastly, I highlight and discuss the trustworthiness enhancing strategies I employed in the present research study.

In Chapter 5, I report on the demographic and clinical characteristics of the recruited sample. Thereafter I present the outcomes of data analysis through four sections. In these sections, I report on how participants understood: (a) MS-F as a symptom, (b) MS-F's impacts on daily life, (c) MS-F management, and (d) coping with MS-F.

In Chapter 6, I discuss and clarify my research findings in relation to existing literature as presented in Chapter 2. Additionally, I also highlight and discuss the theoretical implications and practical utility of the research findings. Subsequently, I emphasise the strengths and limitations of the current research study, whereafter I provide recommendations for future research. Finally, I conclude Chapter 6 with a concise synopsis of the present study's research findings.

1.6 Conclusion

In Chapter 1, I introduced this research study. I provided an overview of MS as a neurodegenerative disorder and highlighted MS as a significant public health concern in SA. This overview involved a concise synopsis of MS's prevalence, aetiology, typical age-of-onset, general prognosis, overarching clinical course, and symptoms. Furthermore, this chapter also provided a preliminary summary of MS-F as a symptom of MS. This summary provided a concise overview of MS-F's aetiology, onset, prevalence, conceptualisation, and its detrimental effect on PwMS. Moreover, in this chapter, I also delineated the RQ, aim and objectives of the present study. As should have been evident, the relative lack of insight into how PwMS understand MS-F as a FOL (both globally and nationally) underscores the need to explore the lived experiences of MS-F amongst PwMS in the WC. Particularly since MS-F seems to be a common, distressing, and debilitating MS-related symptom.

Chapter 2: Literature Review

In the present chapter, I review existent literature on MS-F. In research, either the term “MS fatigue” or “MS-related fatigue” is used when referring to MS attributable fatigue. The term “MS fatigue” is predominantly used when referring to fatigue as a symptom of MS; whilst “MS-related fatigue” is more commonly used in qualitative explorations of MS-F. Despite these terms being synonymous, I have made use of the term “MS fatigue” (MS-F) in this thesis. I start this chapter by defining MS-F, whereafter I discuss MS-F’s aetiological origin. Hereafter, I provide a succinct overview of MS-F’s clinical features so that the reader may develop an overarching understanding of MS-F. Following this overview, I review academic literature and research findings indicative of how PwMS may understand MS-F as a FOL. Here this review occurs through four subsections that pertain directly to the research objectives. That is, I review literature concerning how PwMS may understand: (a) MS-F as a symptomatic experience, (b) MS-F’s impacts on daily life, (c) MS-F management, and (d) coping with MS-F. Finally, I conclude the literature review with a summative conclusion that brings together this chapter’s main points.

2.1 Defining MS Fatigue

MS-F has been described in various ways throughout the literature (Mills & Young, 2008), and there is no agreed upon definition for MS-F (Ayache & Chalah, 2017; Induruwa et al., 2012). The Multiple Sclerosis Council for Clinical Practice Guidelines (MSC) (1998) defines MS-F as: “A subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activities” (p. 2). Whilst dated, the MSC’s (1998) definition is the most commonly cited definition of MS-F, and continues to be used by contemporary MS-F researchers (Blikman et al., 2017; Chen et al., 2020; Chilcot et al., 2016; Nociti et al., 2017; Rooney et al., 2019). Akin to the MSC’s (1998) definition, other definitions of MS-F also centre around subjective experiences within the physical and/or mental domain. Such definitions include descriptions of MS-F being: (a) a perceptual and experiential sense of exhaustion, lack of energy, and tiredness that is distinct from weakness and sadness (Krupp et al., 1988; Lerdal et al., 2007), (b) a difficulty in initiating and/or sustaining voluntary activities (Chaudhuri & Behan, 2004), and (c) an overwhelming tiredness or lack of energy that affects physical and mental functioning (Leocani et al., 2008). Nevertheless, such definitions closely resemble definitions of the fatigue experienced by healthy individuals. Whilst there is no agreement on a single definition for general/normative fatigue (Phillips, 2015; Shen et al., 2006), consider the following definitions: (a) ‘‘an overwhelming sense of tiredness, lack of energy and a feeling of exhaustion, associated with impaired physical and/or cognitive functioning’’ (Shen et al., 2006, p. 70), (b) a “subjectively experienced disinclination to continue performing the task because of perceived reductions in efficiency” (Brown, 1995, p. 156), and (c) “an awareness of a decreased capacity for physical and/or mental activity due to imbalance in the availability, use, and/or restoration of resources needed to perform an activity” (Aaronson et al., 1999, p. 46). When comparing the definitions of MS-F to those of general fatigue, a marked conceptual overlap exists between these definitions. This overlap includes an emphasis on a subjective experience, accompanied by alterations in mental and physical functioning, which impacts functional capacity. Additionally, definitions of MS-F and general fatigue also typically employ the same or similar terminology in their descriptions (e.g. “tiredness”, “lack of energy”, or “exhaustion”). As such, definitions of MS-F that centre on subjective perceptions, whilst insightful, are ambiguous. In an attempt to more clearly define MS-F, Mills and Young (2008) built on, and extended, subjective descriptions of MS-F by defining it as a:

> Reversible, motor and cognitive impairment with reduced motivation and desire to rest, either appearing spontaneously or brought on by mental or physical activity, humidity, acute infection and food ingestion. It is relieved by daytime sleep or rest without sleep. It can occur at any time but is usually worse in the afternoon. In MS, fatigue can be daily, has usually been present for years and has greater severity than any pre-morbid fatigue. (p. 57)

Mills and Young’s (2008) definition, whilst not an agreed upon definition for MS-F (Ayache & Chalah, 2017), is exceptionally useful given its descriptive richness. What I mean by this is that this definition of MS-F extends beyond a description of subjective experience to include aggravating factors, relieving factors, and other associated features. Such a definition provides more defined/tangible parameters to a subjective experience when compared to the MSC’s (1998) definition, and similar descriptions. Consequently, Mills and Young's (2008) definition provides a more specific and less ambiguous means to: (a) conceptually understand MS-F as a clinical entity, and (b) conceptually distinguish MS-F from general fatigue. Accordingly, when thinking about MS-F, it is recommended that Mills and Young’s (2008) definition be recalled alongside the MSC’s (1998) definition.

2.2 MS-F as a Distinct Clinical Entity

In this section, I highlight MS-F as a unique experience that is clinically and experientially distinct from other types of fatigue. I do this by comparing MS-F with “normative” fatigue and the fatigue experienced in other health conditions.

2.2.1 MS-F Compared to General Fatigue

Since fatigue is an experience which all people experience at some point in time (Krupp, 2004), it is essential to distinguish MS-F from the fatigue experienced by healthy individuals (i.e. general/normative fatigue). Whilst PwMS typically use the word “tiredness” or its derivatives (e.g. sleepiness) to describe MS-F (Mills & Young, 2008), MS-F is more than conventional tiredness (Giovannoni, 2006). Existent literature underscores MS-F as unique and different from transient tiredness, general fatigue (Krupp et al., 2010; Turpin et al., 2017), and PwMS’s premorbid fatigue experiences (Flensner et al., 2003; Olsson et al., 2005). With respect to this, MS-F has been found to be more severe than PwMS’s premorbid fatigue experiences (Mills & Young, 2008). Additionally, MS-F has been found to differ from general/normative fatigue by emerging more easily and being liable to heat aggravation (Krupp et al., 1988; Krupp, 2004). Furthermore, it has also been reported that MS-F differs from general fatigue by occurring more frequently, and having more debilitating impacts on everyday activities (Krupp et al., 1988; Krupp, 2004; Newton et al., 2020). Here MS-F’s impact has been found to differ from the impact of general fatigue by: (a) preventing continuous physical activity, (b) inhibiting physical functioning, (c) obstructing role performance, and (d) hindering responsibility fulfilment (Krupp et al., 1988; Krupp, 2004). Considering these impacts, it is unsurprising that PwMS frequently designate MS-F as one of MS's most distressing and/or disabling symptoms (Ayache & Chalah, 2017; Fisk et al., 1994; Jongbloed, 1998; Aygünoğlu et al., 2015). It should, however, be noted that some qualitative overlap exists between MS-F and normative/general fatigue (Krupp, 2003). With reference to this overlap, Krupp et al. (1988) determined that both MS-F and normative/general fatigue worsen after noon, may be aggravated through stress, and might be alleviated through rest. Consequently, whilst MS-F is a unique phenomenon that is clinically distinct from general fatigue, MS-F is not divorced from all general fatigue's characteristic features.

2.2.2 MS-F Compared to Fatigue in Other Clinical Conditions

Fatigue is a symptom which is experienced in various clinical conditions besides MS (Induruwa et al., 2012; Langeskov-Christensen et al., 2017). For example, fatigue is experienced in conditions such as rheumatoid arthritis (RA) (Alikari et al., 2017), human immunodeficiency virus (HIV) (Barroso & Voss, 2013), motor neuron disease (MND) (Gibbons et al., 2013), inflammatory bowel disease (IBD) (Czuber-Dochan et al., 2013), myalgic encephalomyelitis (ME) (Strassheim et al., 2021), endometriosis (DiBenedetti et al., 2020), hepatitis C (Glacken et al., 2003), cancer (Magnusson et al., 1999), Parkinson's disease (Stocchi et al., 2014), ankylosing spondylitis (Dagfinrud et al., 2005), and fibromyalgia (McMahon et al., 2012). Since fatigue may characterise other conditions, it is worth considering how MS-F compares to the fatigue experienced by people with other clinical conditions (PwoCCs).

Researchers assert MS-F as a "type" of fatigue different and distinct from the fatigue characterising other chronic health conditions (Induruwa et al., 2012; Krupp, 2004; Krupp et al., 2010). In particular, the ability of heat to aggravate MS-F has been emphasised as distinguishing MS-F from the fatigue experienced by PwoCCs (Krupp, 2004). Here heat has been well established as a precipitating/aggravating factor of MS-F (Bol et al., 2010; Johnson, 2008; Krupp & Christodoulou, 2001; Lerdal et al., 2007). Nonetheless, MS-F shares some features with the fatigue experienced by PwoCCs (Krupp, 2003). Some of these mutual features have been found to be identical to MS-F and general fatigue's shared features (see subsection 2.2.1) (Krupp et al., 1988). Moreover, PwoCCs suffering from chronic fatigue (e.g. RA) report, akin to PwMS, that their daily activities are affected by a lack of energy as well as physical and/or cognitive changes (Czuber-Dochan et al., 2013; Feldthusen et al., 2013; Gibbons et al., 2013). Consequently, despite assertions that MS-F is distinct from fatigue in other chronic conditions, it is unclear to what degree this assertion holds true.

2.3 The Aetiology of MS Fatigue

The aetiological basis of fatigue in MS has yet to be fully elucidated and understood (Bol et al., 2009; Induruwa et al., 2012; Langeskov-Christensen et al., 2017). Nonetheless, it appears that multiple factors and mechanisms are causal to the development and perpetuation of MS-F in MS (Induruwa et al., 2012; Kos et al., 2008). Whilst these mechanisms and factors remain poorly understood and contentious in literature (Ayache & Chalah, 2017; Bisecco et al., 2016; Kantarci & Wingerchuk, 2006), they have been categorised into two co-contributing MS-F subtypes (Dalgas et al., 2018; Kos et al., 2008; Langeskov-Christensen et al., 2017). Depending on the class of aetiological mechanisms implicated, MS-F may be subtyped into either primary or secondary fatigue (Dalgas et al., 2018; Langeskov-Christensen et al., 2017). Primary fatigue refers to fatigue emanating directly from MS-mediated damage to the CNS through processes such as inflammation, demyelination, and axonal loss (amongst others). In contrast, secondary fatigue refers to fatigue arising from non-disease specific factors such as psychological functioning, depression, anxiety, heat sensitivity, pain, sleep problems, medication use, and deconditioning (amongst others) (Kos et al., 2008; Langeskov-Christensen et al., 2017). Whilst MS-F comprises both primary and secondary fatigue (Dalgas et al., 2018; Kos et al., 2008), MS-F largely emanates from CNS-related neuropathology (Comi & Leocani, 2002; Krupp, 2004; Langeskov-Christensen et al., 2017). Consequently, MS-F appears to be a symptom largely comprised of primary fatigue.

2.4 Overview of MS-F's Clinical Features

In this section, I provide a concise, yet non-exhaustive, synopsis of MS-F's clinical features and trends as informed by pertinent quantitative literature. Some aforementioned information is briefly noted here and expanded on in further detail. Through this section, I hope to provide a basic overview of MS-F as a clinical entity for the reader. This overview is essential to contextualising MS-F as a symptom and underscores the present study's research methodology. Within this section, I will review MS-F's onset, MS-F as a temporal and chronic symptom, as well as the relationship between MS-F and MS's clinical features.

2.4.1 MS-F's Onset

Whilst MS-F may develop at any point during MS's progression (Comi et al., 2001; Kos et al., 2004), MS-F typically has its onset at, or near, the time of MS onset (Whitaker & Mitchell, 1997). Since MS onset typically occurs during early adulthood (MSIF, 2013) between the ages of 20 and 40 years (Modi et al., 2008; Sadock, et al., 2015), MS-F thus tends to affect young and middle-aged adults at their peak physical and economic potential (Stuifbergen & Rogers, 1997). MS-F may be the principal presenting symptom of MS by preceding the onset of other MS symptoms (Debouverie et al., 2008; Krupp 2004; Lezak et al., 2012). Nonetheless, a recent population-based study by Yusuf et al. (2020) suggests that MS-F is unlikely to be the onset symptom of MS. Yusuf et al. (2020) determined that amongst Canadian MS sufferers (*N* = 6863), pain was the most prevalent symptom (50.2%) prior to their participants first demyelination event. Pain was followed, in order of prevalence, by sleeping disorders (7.7%), anaemia (3.4%), and fatigue (2.5%) (Yusuf et al., 2020). Accordingly, whilst MS-F may be MS's principle presenting symptom; it seems unlikely that MS-F would be MS's principle presenting symptom.

2.4.2 MS-F as a Temporal yet Chronic Symptom

Following its onset, MS-F tends to persist across and throughout the lives of PwMS (Whitaker & Mitchell, 1997). In respect to this, MS-F constitutes a temporal symptom (i.e. an episodic phenomenon) that PwMS continuously experience throughout their lives (Mills & Young, 2008). PwMS may experience MS-F on a daily basis (Johnson et al., 2004; Krupp et al., 2010; Mills & Young, 2008), however, the typical duration of an MS-F episode appears to vary between PwMS (Fisk et al., 1994). Some PwMS report MS-F episodes to last, in general, for less than 6 hours; whilst other PwMS report that MS-F episodes typically last between 6 and 24 hours (Fisk et al., 1994).

2.4.3 MS-F and MS's Clinical Features

There is little literary consensus on the relationship between MS-F and MS's clinical features in existing literature (Mills & Young, 2011; Rooney et al., 2019). This lack of consensus is unsurprising since PwMS's subjective experience of MS-F does not consistently relate with any objective physical signs or neurological impairment (Ayache & Chalah, 2017; Kos et al., 2008; Leocani et al., 2008). To illustrate this inconsistency, I provide a concise review of how MS-F relates to MS-related disability level, disease duration, MS subtypes, MS-relapses, and other MS related symptoms/conditions.

2.4.3.1 MS-F and MS-related Disability Level. A great number of studies have investigated the relationship between MS-F and MS-related disability level. Whilst several studies have found a statistically significant relationship between MS-F and disability level (Fiest et al., 2016; Flachenecker et al., 2002; Kroencke et al., 2000; Lerdal et al., 2007; Mills & Young, 2011; Schreurs et al., 2002); other researchers identified no such relationship (Bakshi et al., 2000; Fisk et al., 1994; Koch et al., 2009; Krupp et al., 1988). As such, there exists no consensus on the relationship between MS-F and MS-related disability level (Rooney et al., 2019). Moreover, it appears that MS-related disability level is incapable of consistently accounting for the presence/severity of MS-F (Bakshi, 2003; Fisk et al., 1994; Ford et al., 1998; Lezak et al., 2012).

2.4.3.2 MS-F and Disease Duration. Some research suggests that MS-F severity increases with disease duration (Johansson et al., 2008; Lerdal et al., 2007; Schreurs et al., 2002). However, other studies have not identified a statistically significant relationship between disease duration and MS-F (Bakshi et al., 2000; Fisk et al., 1994; Flachenecker et al., 2002; Mills & Young, 2011). As such, and as noted by Rooney et al. (2019), it is clear that no literary consensus exists on MS-F's relation to disease duration.

2.4.3.3 MS-F and MS-Subtypes. As noted in Chapter 1, MS can be categorised into four MS-subtypes depending on the broad clinical course the disease follows (i.e. RRMS, PPMS, SPMS, and PRMS) (Courtney et al., 2009). Whilst research overwhelmingly emphasises MS-F as more common amongst progressive MS sufferers (Bakshi et al., 2000; Barak & Achiron, 2006; Colosimo et al., 1995; Leocani et al., 2008; Lerdal et al., 2007; Rooney et al., 2019), MS-F may develop irrespective of the MS subtype (Bakshi, 2003; Krupp et al., 2010) and disease course (Kos et al., 2008; Lezak et al., 2012). Given these findings, it is unsurprising that MS subtypes have been found to be incapable of accounting for the presence of MS-F (Bakshi, 2003). Nonetheless, research has been relatively consistent in identifying MS-F as more severe amongst progressive MS subtypes (Colosimo et al., 1995; Johansson et al., 2008; Koch et al., 2009; Kroencke et al., 2000; Lerdal et al., 2007; Mills & Young, 2011; Patrick et al., 2009). Consequently, it is reasonable to conclude that MS-F is more severe for progressive MS subtypes.

2.4.3.4 MS-F and MS-Relapses. MS-F constitutes a major feature of MS-relapses (Mills & Young, 2008) in that MS-F may herald or accompany MS-relapses (Comi et al., 2001). Research consistently reports that MS-F during relapses are more severe for PwMS (Flachenecker et al., 2004; Flachenecker & Meissner, 2008; Hanken et al., 2014; Heesen et al., 2006; Kos et al., 2008). This consensus posits MS-F experiences during an MS-relapse as an outlier with respect to PwMS's typical MS-F experiences. Accordingly, PwMS who present with an MS-relapse may introduce artefacts into research more generally aimed at MS-F.

2.4.3.5 MS-F's and Other Symptoms/Conditions. PwMS's subjective experience of MS-F does not consistently relate with other MS related symptoms/conditions and mental disorders (e.g. depression) (Ayache & Chalah, 2017; Iriarte et al., 2000; Leocani et al., 2008). Notwithstanding this, MS-F may arise from, or be exacerbated by, various symptoms/conditions common in MS. This includes, for example, sleep disturbances, depression, anxiety, pain, motor disruptions, and weakness (Ayache & Chalah, 2017; Comi et al., 2001; Induruwa et al., 2012; Krupp, 2004; Leocani et al., 2008). Whilst there are various MS related symptoms/conditions which may affect MS-F; depression and pain are the most noteworthy.

A great deal of research has attempted to determine the relationship between MS-F and depression. Whilst most studies have identified a statistically significant relationship between MS-F and depression (Andreasen et al., 2010; Bakshi et al., 2000; Brenner et al., 2018; Brown et al., 2009; Fiest et al., 2016; Koch et al., 2009; Lerdal et al., 2007; Mills & Young, 2011; Téllez et al., 2006; Wood et al., 2013), some studies have failed at demonstrating a relationship (Fisk et al., 1994; Iriarte et al., 2000; Krupp et al., 1988). Nonetheless, researchers generally accept depression as contributing to MS-F (Kaminska et al., 2011; Krupp et al., 2010; Langeskov-Christensen et al., 2017). Furthermore, authors commonly cite MS-F as being related to pain (Kos et al., 2008; Krupp et al., 2010; Langeskov-Christensen et al., 2017; Tur, 2016). Whilst Patrick et al.'s (2009) study conducted with PwMS in the US (N = 2,768) is the only study (to my knowledge) reporting a significant relationship (r = .321) between MS-F severity and pain severity; there is evidence for a relationship between fatigue and pain in other conditions such as RA (Pollard et al., 2006; van Dartel et al., 2013; Wolfe et al., 2004) and leukaemia (Miladinia et al., 2018). Therefore, it seems likely that MS-F and pain are related in MS.

2.5 The Lived Experiences of MS-F

Within this section, I review the existing literature on PwMS’s lived experiences of MS-F. That is, I review scholarly insights into how PwMS seem to understand and conceptualise: (a) MS-F’s symptomatic experience, (b) MS-F’s impacts on daily life, (c) MS-F management, and (d) coping with MS-F. Given the marked lack of research into PwMS’s lived experiences of MS-F, this review relied heavily on a few phenomenological studies on MS-F (Flensner et al., 2003; Johnson et al., 2004; Olsson et al., 2005) and findings on how PwMS conceptualise their experience of MS-F (Blaney & Lowe-Strong, 2009; Gagliardi, 2003; Kayes et al., 2011; Mills & Young, 2008; Moriya & Kutsumi, 2010; Smith et al., 2015; Stuifbergen & Rogers, 1997). Importantly, in the following subsections, emphasis is placed on understandings and sense-making as opposed to descriptions of living with MS-F. Nevertheless, where relevant and appropriate, perceptions and conceptions are considered in relation to how PwMS have described MS-F as a FOL.

2.5.1 PwMS's Understanding of MS-F as a Symptomatic Experience

Existent literature suggests that PwMS may consider/perceive a lack of energy as a central feature of MS-F (Flensner et al., 2003; Mills & Young, 2008; Newton et al., 2020; Olsson et al., 2008; Stuifbergen & Rogers, 1997). The most compelling case for this perception is Flensner et al.'s (2003) phenomenological exploration of how Swedish PwMS (*N* = 9) understood MS-F. PwMS in Flensner et al.'s (2003) study perceived MS-F as involving a "loss of energy" (p. 711) and considered MS-F to signify reductions in energy and strength. These restrictions were regarded as an unavoidable and paralytic force which rapidly invades the body as if "energy disappeared like discharging a battery" (p. 711). Akin to Flensner et al.'s (2003) finding, other PwMS have also designated MS-F as typified by an energetic depletion (Mills & Young, 2008; Olsson et al., 2008; Stuifbergen & Rogers, 1997). Consider for instance Stuifbergen and Rogers's (1997) theme "The undertow effect of severe fatigue" (p. 6) identified in a descriptive study conducted on American PwMS (*N* = 13). This theme represented participants' tendency to describe severe MS-F as characterised by energy impoverishment and a complete powerlessness (Stuifbergen & Rogers, 1997). Given these findings, it is unsurprising that Newton et al.'s (2020) thematic synthesis of qualitative inquiries into MS-F (*N* = 9) identified a lack/loss of energy as implicated in MS-F experiences. Furthermore, PwoCCs have also highlighted a lack of energy as central to fatigue in conditions such as RA (Feldthusen et al., 2013) and MND (Gibbons et al., 2013). Consequently, preceding research suggests that PwMS's self-appraised energetic state may be implicated in how they understand MS-F as a symptom.

Research further suggests that PwMS may perceive/conceptualise MS-F as a subjective and/or embodied phenomenon (Flensner et al., 2003; Moriya & Kutsumi, 2010; Smith et al., 2015). For instance, Moriya and Kutsumi (2010) identified that PwMS in Japan (*N* = 10) "perceived fatigue with their subjective sensations” (p. 423) such as through sensations of sleepiness or being rooted. Furthermore, some researchers have reported that PwMS perceive MS-F as involving subjective physical and cognitive experiences (Flensner et al., 2003; Smith et al., 2015). For example, Flensner et al. (2003) identified that PwMS perceived MS-F within their physical bodies, and regarded MS-F as involving cognitive impairments (e.g. impaired concentration). Likewise, Smith et al.'s (2015) interpretative descriptive study found that male PwMS (*N* = 18) in NZ considered MS-F to have both physical and cognitive implications.

When speaking about the fatigued body, PwMS tend to highlight MS-F as either a whole body experience or a localised experience occurring in select parts of the body – e.g. the head or muscles (Flensner et al., 2003; Mills & Young, 2008; Olsson et al., 2005; Smith et al., 2015). Furthermore, PwMS have also described various temporal physical phenomena as typifying and/or accompanying MS-F. These physical phenomena involve experiences such as weakness, heaviness, pain, tremors, paraesthesia (i.e. numbing), ambulatory impairments (e.g. walking difficulties), a loss of balance, motor speech impairment (e.g. slurred speech), and visual disturbances (Blaney & Lowe-Strong, 2009; Flensner et al., 2003; Mills & Young, 2008; Newton et al., 2020; Smith et al., 2015; Stuifbergen & Rogers, 1997). When speaking about the fatigued mind, PwMS described various temporal mental alterations as accompanying and/or distinctive of MS-F. These mental alterations denoted mental impairments and were described as encompassing impaired concentration, a loss/lack of mental clarity, impaired memory and recall, impaired attention, and language processing deficits (Blaney & Lowe-Strong, 2009; Johnson et al., 2004; Mills & Young, 2008; Newton et al., 2020; Stuifbergen & Rogers, 1997). Notably, PwoCCs have also designated chronic fatigue as typified by physical and cognitive involvements. This includes how chronic fatigue is experienced in conditions such as RA (Feldthusen et al., 2013), MND (Gibbons et al., 2013), IBD (Czuber-Dochan et al., 2013) and hepatitis C (Glacken et al., 2003). Accordingly, existent literature indicates that PwMS may perceive MS-F’s symptomatic experience through subjective bodily and mental phenomena.

Research further suggests that PwMS may perceive and consider MS-F as being an inevitable experience that persists across life (Flensner et al., 2003; Olsson et al., 2005; Stuifbergen & Rogers, 1997). Olsson et al. (2005) identified that Swedish women living with MS (*N* = 10) considered MS-F to be an ever-present and never-ending subjective experience. For these PwMS, MS-F denoted a constant and unrelenting subjective experience which endured despite rest and/or sleep (Olsson et al., 2005). Similarly, Flensner et al. (2003) found that PwMS perceived MS-F as a “time consuming and all absorbing” (p. 711) phenomenon. These PwMS regarded MS-F as a near ever-present, inescapable, and sporadic symptom which always needed to be considered. Likewise, Stuifbergen and Rogers (1997) identified that PwMS conceptualised MS-F as an “ever-present ongoing experience” (p. 5). Here MS-F constituted an incessant and continuous symptom which sleep could not alleviate (Stuifbergen & Rogers, 1997). Moreover, people with RA have also highlighted fatigue as an unrelenting and ongoing experience (Feldthusen et al., 2013). As such, it appears that PwMS may understand MS-F as a symptom through its persistence and inescapability.

2.5.2 PwMS’s Understanding of MS-F’s Impacts on Everyday Life

The terms “daily life” and “everyday life” are recurrently used in this thesis. The term “daily” is an adjective which may be defined as “happening, done, or produced every day” (Oxford University Press, 2021a, para 1) and relates to the course of a single day (Lexico, 2021a). Similarly, “everyday” is an adjective which means “used or happening every day or regularly” (Oxford University Press, 2021b, para 1) and refers to that which is commonplace and ordinary (Lexico, 2021b). As highlighted by Mosvold (2005), these descriptions suggest that both “daily life” and “everyday life” refers to phenomena (e.g. activities, tasks, or events) that occur/happen regularly (i.e. typically, commonly, and ordinarily). Since both “daily life” and “everyday life” pertain to typical/common phenomena in life (Mosvold, 2005), I used these terms interchangeably to refer to the typical/ordinary aspects which characterise PwMS’s lives. Having clarified the concept of daily/everyday life, I now review the literature on how PwMS seem to understand MS-F’s impacts on daily life.

There exists some evidence that PwMS may perceive MS-F as limiting or restricting them in living life (Flensner et al., 2003; Olsson et al., 2005). For instance, Olsson et al. (2005) found that living with MS-F signified a restricted and limited ability for PwMS to live life. Similarly, Flensner et al. (2003) identified that living with MS-F meant living with “restrictions of life” (p. 712). In Flensner et al.'s (2003) study, participants conveyed this insight by describing MS-F attributable changes in their lives (i.e. changes in their familial, social, occupational, and domestic lives) as restrictions typifying their lives. With respect to such changes, PwMS have described experiencing undesirable emotions such as sorrow, shame, and guilt (Flensner et al., 2003; Newton et al., 2020).

Perceiving a restricted life as an everyday consequence of MS-F is also complementary to how PwMS conceptualise MS-F’s effects on life (Irvine et al., 2009; Kayes et al., 2011; Moriya & Kutsumi, 2010; Smith et al., 2015; Stuifbergen & Rogers, 1997). Consider for instance Stuifbergen and Rogers' (1997) theme termed the “pervasive impact of fatigue on life” (p. 5). This theme denotes how MS-F’s limitations, and the potential for future MS-F, affected almost every decision their participants made in life. Here MS-F necessitated lifestyle changes and sacrifices in life such as working less hours and not pursuing career advancement (Stuifbergen & Rogers, 1997). Alternatively, consider Moriya and Kutsumi’s (2010) finding that PwMS emphasised MS-F as distruptive to task-performance and the ability to live a “normal” life. In this study, PwMS designated MS-F as affecting both their lifestyle and their ability to be true to themselves (Moriya & Kutsumi, 2010). Akin to such findings, Smith et al. (2015) found that MS-F diminished the control male PwMS had over their everyday life, whilst Kayes et al. (2011) identified MS-F as a barrier to PwMS’s (*N* = 10) participation in physical activities in NZ. Moreover, fatigue has also been found to restrict the lives and activities of those suffering from RA (Feldthusen et al., 2013; Thomsen et al., 2015), ME (Strassheim et al., 2021), IBD (Czuber-Dochan et al., 2013). In its entirety then, it appears that MS-F is central in directing and constraining PwMS’s everyday lives. Something which may itself be accompanied by negatively valanced emotions.

Building on this, research further suggests that PwMS may perceive/consider a functional disruption as a typical consequence/impact of MS-F (Flensner et al., 2003; Kayes et al., 2011; Mills & Young, 2008; Moriya & Kutsumi, 2010; Stuifbergen & Rogers, 1997). For instance, participants in Flensner et al.'s (2003) study perceived a dramatic loss of energy as a paralytic force that inhibited functional continuance. Here, with reference to severe MS-F episodes, Flensner et al. (2003) reports: “When the respondents felt totally drained of energy, they could not manage anything further. It was absolutely impossible to continue to walk or even to take one single step more.” (p. 711). Similarly, Stuifbergen and Rogers (1997) identified a theme “fatigue as a paralysing force” (p. 5) to represent how PwMS perceived themselves as powerless to function when fatigued. Likewise, PwMS in Kayes et al.'s (2011) study, considered physical activity as feasible only if the energetic demand of said activity was not too great; whilst Mills and Young (2008) identified a perceived lack of motivation for sustaining and completing tasks as implicated in MS-F. Moreover, functional disruptions and demotivation has also been reported by those suffering from chronic fatigue in endometriosis (DiBenedetti et al., 2020), ME (Strassheim et al., 2021), and MND (Gibbons et al., 2013). Taken together, it appears that the functional disruptions of MS-F may be implicated in how PwMS understand MS-F’s impacts on daily life.

Notably, PwMS have reported experiences of undesirable emotions because of an MS-F attributable functional impairment. Emotions such as despair, sorrow, worthlessness, anger, and sadness have been reported as emanating from impaired functioning (e.g. walking difficulty), a loss of functional capacity (e.g. inability to walk), and failed task-performance when fatigued (Flensner et al., 2003). Some evidence even suggests that the mere potential for future functional impairment may result in MS-F sufferers experiencing negative emotions (Olsson et al., 2008). Furthermore, emotions such as fear, worry, and anxiety also appear to emanate from MS-F sufferers’: (a) self-perceived ability to function and perform tasks, and (b) meta-perceptions of how others perceive their functioning (Newton et al., 2020). These findings suggest that if PwMS perceive MS-F as disrupting their everyday functioning; this disruption would be a prominent concern for PwMS.

Lastly, there is some evidence suggesting that MS-F leads to a loss of independence in PwMS's everyday lives (Flensner et al., 2003; Newton et al., 2020). Flensner et al. (2003) found that PwMS suffering from MS-F perceived themselves as helpless and dependent on others. Participants in this study conveyed this perception by highlighting the fatigued self as reliant on others and having to live a structured life (Flensner et al., 2003). Whilst Newton et al.'s (2020) thematic synthesis identified a loss of autonomy and dependency as implicated in PwMS' experience of MS-F; no author besides Flensner et al. (2003) has reported diminished independence as an everyday impact of MS-F. Nonetheless, it remains possible that living with MS-F may signify living a less independent life. Furthermore, since PwMS have described a reliance on others as difficult (Olsson et al., 2008), it seems likely that a loss of independence could be a prominent concern and challenge for MS-F sufferers' in life. However, this postulate is predicated on PwMS ascribing to a notion that life with MS-F is typified by a subverted independence.

2.5.3 PwMS's Understanding of Managing MS-F

"Management" or "self-management" is a developing concept in neurological literature (Audulv et al., 2016) which, despite its widespread use, remains ill defined. Management is frequently defined in accordance with Corbin and Strauss's (1988) work as the "medical or behavioural management, role management, and emotional management" (Lorig & Holman, 2003, p. 1) required when living with a chronic condition (Audulv et al., 2016). Nevertheless, Wilkinson and Whitehead (2009) offer a more descriptively rich and tangible conceptualisation of management. They posit management as pertaining to an individual's ability to successfully manage the symptoms, treatment, consequences, and lifestyle changes needed to live with chronic disease (Wilkinson & Whitehead, 2009). In line with Wilkinson and Whitehead (2009), Audulv et al.'s (2016) concept analysis of "self-management" in neurological literature found that self-care centred around:

1. Disease-controlling strategies aimed at controlling symptoms, limiting complications, and/or curtailing disease progression (e.g. medicine or avoiding symptom triggers).

2. Healthy lifestyle behaviours directed at enhancing health and reducing the risk for lifestyle attributable illness (e.g. exercise, sleep, rest, or following a healthy diet).

Importantly, Miller et al.'s (2015) research suggests that a discrepancy may exist between how researchers define management and how chronic disease sufferers describe management. Thus, whilst literary insight into management as a concept is useful; such insight should not be regarded as exemplative of lay conceptions of management. Nonetheless, with a concept of management in mind, I now review how PwMS seem to understand MS-F management.

Existent research suggests that PwMS perceive and consider a structured/planned approach to life as valuable to effective MS-F management (Blaney & Lowe-Strong, 2009; Flensner et al., 2003; Malcomson et al., 2008; Moriya & Kutsumi, 2010). For instance, Flensner et al. (2003) found that MS-F sufferers perceived within themselves a desire for living a structured life. In Flensner et al.'s (2003) study, participants attempted to circumvent MS-F onset by planning for the future and scheduling both task-performance and rest. Likewise, MS-F sufferers in the UK (*N* = 10) highlighted scheduling activities and rest as central to successfully performing and completing activities (Blaney & Lowe-Strong, 2009). Furthermore, PwMS in Northern Ireland (*N* = 13) have highlighted planning as a route to overcoming the MS-F’s restrictions on daily life (Malcomson et al., 2008); whilst PwMS in the USA (*N* = 14) scheduled important activities/tasks in order to compensate for MS-F’s everyday consequences (Johnson et al., 2004). Akin to such findings, Moriya and Kutsumi (2010) identified MS-F management as involving “measures to predict and control activity and rest” (p. 423). Participants in Moriya and Kutsumi's (2010) study deliberately rested for future activities/plans and avoided certain activities to achieve target activities/tasks. Here MS-F management was aimed at ensuring that MS-F and activity could coexist (Moriya & Kutsumi, 2010). Moreover, PwoCCs have highlighted planning/preparation as a valuable way by which to manage fatigue in RA (Feldthusen et al., 2013), MND, (Gibbons et al., 2013), IBD (Czuber-Dochan et al., 2013), and cancer (Magnusson et al., 1999). All things considered; existent research findings suggest that MS-F management implies some form of planning/preparation.

Moreover, research also suggests that planning/preparation is enacted by PwMS with an intent of circumventing MS-F and curtailing MS-F's functional disturbances. Nonetheless, it should be noted that some PwMS have described planning as difficult because of MS's physical impairments (Olsson et al., 2008). Consequently, if MS-F management involves planning/preparation; this planning/preparation could itself be challenging/demanding for some MS-F sufferers.

Prior research further indicates that energy maintenance may denote and/or constitute a means to (i.e. a way to) MS-F management (Blaney & Lowe-Strong, 2009; Flensner et al., 2003; Smith et al., 2015; Stuifbergen & Rogers, 1997). For instance, Blaney and Lowe-Strong (2009) found that PwMS considered energy efficiency strategies as a way by which to manage MS-F. Consistent with this, Stuifbergen and Rogers (1997) identified that PwMS employed "energy conservation" (p. 7) and "recharge efforts" (p. 7) as MS-F management strategies. Here the theme "energy conservation" (p. 7) comprised self-care strategies which PwMS used to reduce energy consumption and, thereby, postpone functional impairment. Such strategies included doing less, receiving help from others, and "working smart" (Stuifbergen & Rogers, 1997, p. 7) by minimising energy expenditure during task-performance. Similarly, Johnson et al. (2004) found that energy conservation was an important way by which PwMS managed fatigue and maintained employment.

Moving on, Stuifbergen and Rogers's (1997) theme "recharge efforts" (p. 7) encompassed self-care strategies which PwMS used to restore energy and/or attentional capability. Such strategies included: (a) a planned/needed cessation of activity through rest, (b) diversional activities which distracted PwMS from distress when fatigued, (c) promoting rest and sleep through medications, and (d) elevating energy levels through stimulant use (e.g. caffeine). Other researchers (Flensner et al., 2003; Moriya & Kutsumi, 2010; Mozo-Dutton et al., 2012) have obtained findings related to, yet different from Stuifbergen and Rogers (1997). For instance, Flensner et al. (2003) found that participation in positive and meaningful acts (e.g. recreational activities) facilitated MS-F management by distracting PwMS from MS-F. Similarly, Moriya and Kutsumi (2010) identified MS-F management as involving "measures by conscious thought" (p. 423) such as not thinking and positive thinking. Whilst Flensner et al. (2003) and Moriya and Kutsumi's (2010) findings do not link cognitive redirection to energy maintenance; such a link is reported in an IPA study conducted by Mozo-Dutton et al. (2012) on British PwMS (*N* = 12). In this study, PwMS perceived a cognitive relocation of MS to a less prominent position as a way by which mental capacity and energy could be freed up. As such, Mozo-Dutton et al.'s (2012) findings align with Stuifbergen and Rogers's (1997) theme “recharge efforts” (p. 7) as presented previously. Moreover, Mozo-Dutton et al.'s (2012) findings also posit cognitive relocation/measures [such as those identified by Flensner et al. (2003) as well as Moriya and Kutsumi (2010)] within the realm of energy maintenance.

Convergent with evidence positing energy maintenance as a means to MS-F management (Blaney & Lowe-Strong, 2009; Flensner et al., 2003; Mozo-Dutton et al., 2012; Stuifbergen & Rogers, 1997), research reports energy maintenance as the goal/intent of MS-F management strategies (Malcomson et al., 2008; Mills & Young, 2008; Smith et al., 2015). Consider, for instance, Smith et al.'s (2015) identification that male PwMS managed MS-F in the context of exercise by “reprioritising activities” (p. 184). In a manner comparable with “working smart” (Stuifbergen & Rogers, 1997; p. 7), PwMS in Smith et al.'s (2015) study reprioritised activities (i.e. chose certain activities over others) with the intent to optimise the use of their limited energy reserves. Likewise, Malcomson et al. (2008) found that PwMS regarded pacing as a strategy by which to attain sufficient energy to endure daily life; whilst PwMS in Mills and Young's (2008) study designated rest as a means to “store up energy” (p. 55) in preparation for future functioning. Moreover, energy maintenance has also been identified as a route to MS-F maintenance in conditions such as RA (Feldthusen et al., 2013), IBD (Czuber-Dochan et al., 2013) and MND (Gibbons et al., 2013). Considered as a whole, existent research suggests that MS-F management implies energy maintenance in some shape or form. This postulate gains further plausibility when considering that PwMS seemingly regard MS-F as involving a lack of energy (Flensner et al., 2003; Olsson et al., 2008; Stuifbergen & Rogers, 1997). Here, common-sense reasoning suggests that if

MS-F as a symptom implies an energy deficiency; MS-F management would (to some degree) seek to curtail said energy deficiency.

As previously highlighted, it appears that a structured/planned approach to life and energy maintenance are implicated in how PwMS understand MS-F management. Nonetheless, researchers have reported MS-F management strategies which were not explicitly linked with either planning or energy maintenance. This includes MS-F management strategies such as massaging, stretching (Moriya & Kutsumi, 2010), temperature regulation (Mills & Young, 2008; Stuifbergen & Rogers, 1997), enhancing resistance to MS-F (e.g. through exercise or good nutritional practices) (Mills & Young, 2008; Stuifbergen & Rogers, 1997), and taking life day by day (Flensner et al., 2003). Whilst these management strategies may be implicated in planning and/or energy maintenance; such a deduction is speculative since these strategies may feature in an alternate perception of MS-F management. Furthermore, it should be noted that some PwMS have designated MS-F management strategies as incapable of completely and consistently alleviating MS-F (Mills & Young, 2008; Moriya & Kutsumi, 2010). For instance, PwMS have emphasised nocturnal sleep to be unrefreshing in general, and often incapable of alleviating MS-F (Mills & Young, 2008). Moreover, some PwMS have also described MS-F management as giving rise to problems (e.g. employment difficulties) (Moriya & Kutsumi, 2010). Taken together, such findings suggest that PwMS may espouse varied notions regarding the efficacy, dependability, and implications of MS-F management. Accordingly, it seems that the perceived utility of select MS-F management strategies may vary between different PwMS.

2.5.4 PwMS's Understanding of Coping

Coping represents a more cohesive and developed concept than management (Audulv et al., 2016). Most contemporary definitions of coping emanate from Lazarus's (1966) seminal work who later defined coping as: "constantly changing cognitive and behavioural effort 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). Lazarus and Folkman's (1984) definition, whilst dated, underscores most contemporary definitions of coping (Audulv et al., 2016). This includes the American Psychological Association's (APA) (2020) definition which describes coping as:

> The use of cognitive and behavioral strategies to manage the demands of a situation when these (i.e., the demands) are appraised as taxing, or exceeding one’s resources, or to reduce the negative emotions and conflict caused by stress. (Coping, para. 1)

Audulv et al.'s (2016) concept analysis of coping in neurological literature yielded findings consistent with both Lazarus and Folkman’s (1984) and the APA's (2020) definitions. In their study, coping was found to be a concept that centred around the use of mental and activity-based strategies to deal with taxing/demanding challenges (Audulv et al., 2016). Moreover, Audulv et al. (2016) demonstrated that coping differed from management in that coping was less concerned with disease-controlling strategies and healthy lifestyle behaviours. Thus, whilst management seeks to curtail or improve a disease/symptom; coping centres around dealing with taxing/demanding challenges or undesirable emotions.

With the concept of coping in mind, it appears that PwMS perceive/consider an acceptance of MS-F as important to coping with MS-F (Flensner et al., 2003; Moriya & Kutsumi, 2010; Newton et al., 2020; Turpin et al., 2017). This acceptance is best illustrated through Flensner et al.'s (2003) finding that MS-F sufferers perceived in themselves a “desire for acceptance of life” (p. 712). In conveying this perception, participants in Flensner et al.'s (2003) study spoke about a “fighting spirit” (p. 712) and attempts at maintaining functional capacity. Concurrently, these participants designated the acceptance of MS-F and its functional limitations as paramount to coping with MS-F. It was through a “fighting spirit” and the acceptance of MS-F and its functional limitations that PwMS in Flensner et al.’s (2003) study could live with MS-F.

Acceptance as a means to effectively cope with MS-F also aligns with the results from other qualitative studies (Moriya & Kutsumi, 2010; Newton et al., 2020; Turpin et al., 2017). For instance, Moriya & Kutsumi (2010) found that PwMS perceived living with MS-F to involve an acceptance of MS-F, MS-F management, and limitations (Moriya & Kutsumi, 2010). Likewise, Turpin et al. (2017) identified that Australian PwMS (*N* =13) adjusted their lives and expectations to accommodate MS-F through acceptance; whilst Newton et al. (2020) found that an acceptance of MS-F enhanced PwMS's perceived capacity to cope with and manage MS-F. Several descriptive qualitative findings are also convergent with the afore presented findings (Malcomson et al., 2008; Olsson et al., 2008; Smith et al., 2015). For example, female PwMS have spoken about fighting to maintain their occupational lives in spite of severe MS-F (Olsson et al., 2008), whilst male PwMS have described determination as a personality trait that permits them to achieve their goals despite MS-F (Smith et al., 2015). Similarly, PwMS in Malcomson et al.'s (2008) study highlight a concerted effort and having to "push" (p. 668) as essential for participating in social/familial activities. Considering Malcomson et al.'s (2008) finding, along with those of Olsson et al. (2008) and Smith et al. (2015), it seems that a "fighting spirit" or "pushing through" may facilitate and/or determine goal attainment and task-performance. In this sense then, it appears that coping with MS-F may imply an acceptance of MS-F and its impacts.

2.6 Conclusion

In this chapter, I provided a concise yet in-depth overview of the contemporary understanding of MS-F in existing literature. As was evident, researchers have yet to reach a consensus on MS-F's definition. Nevertheless, MS-F is a clinical symptom that is distinct from the fatigue experienced by healthy individuals. Here research consistently highlights MS-F to be a multidimensional and multicausal symptom with a complex aetiology. Whilst research has made advancements in delineating MS-F's clinical features; the relation between MS-F and a myriad of variables (e.g. neurological impairment) are yet to be conclusively established. Furthermore, only a few research studies have explored how PwMS understand, perceive, and conceptualise MS-F as a FOL. Despite this scarcity, these studies generated findings that provided some tentative insight into how PwMS in the WC may understand: (a) MS-F as a symptom, (b) MS-F's impacts on everyday life, (c) MS-F management, and (d) coping with MS-F. As should have been evident, these findings and insights were markedly convergent and consistent. Nonetheless, such convergence should not be taken as illustrative of a theoretical saturation on PwMS’s understanding of MS-F as a FOL. This conclusion is premature given the relative absence of research studies that attempt to understand MS-F in a phenomenological manner. Moreover, it is also premature to assume that findings and insights from existing literature reflect PwMS’s lived experiences of MS-F in the WC.

Chapter 3: Research Paradigm and Theoretical Orientation

In this chapter, I discuss the research paradigm and theoretical framework I adopted in the present study. I start this chapter by designating constructivism as my espoused worldview and discuss it in terms of its ontological and epistemological stances. Subsequently, I present IPA as the theoretical orientation I used to explore PwMS's lived experiences of MS-F. I discuss IPA as the theoretical orientation by delving into IPA's theoretical influences (i.e. phenomenology, hermeneutics, and ideography). In presenting IPA as a theoretical orientation, I also highlight how IPA's theoretical influences informed my research methodology and approach to data analysis. Hereafter, I distinguish between what I mean by the term "experience" and "lived experience" in the present study. Subsequently, I present my reasons for adopting IPA as a theoretical orientation, whereafter I highlight some critiques of IPA. All in all, this chapter will make explicit the philosophical and theoretical underpinnings of the present study.

3.1 Research Paradigm

I adopted a constructivist worldview in accordance with Guba and Lincoln (1994) in planning and executing the research. This research paradigm is characterised by ontological relativism as well as a transactional and subjectivist epistemology (Guba & Lincoln, 1994). I present and discuss these philosophical stances in the ensuing subsections.

3.1.1 Ontological Relativism

I adopted a relativist stance by assuming the existence of a subjective reality characterised by various social constructions of the meaning of reality. I considered humans to be sense-making creatures that seek to understand and make sense of their lived worlds. Here I regarded meaning as constructed through individuals' subjective experiences as mediated by social, contextual, and historical factors (Creswell, 2014a; Guba & Lincoln, 1994). Moreover, I also assumed that individuals constructed numerous and varied meanings of their experiences in their lived worlds. As such, I regarded individuals as capable of constructing meanings which could either converge or diverge (Guba & Lincoln, 1994). Nonetheless, by adopting a relativist stance, I also assumed that distinct meanings could not be differentiated as more/less true in any absolute/objective sense. Much rather, different meanings where thought of as only varying in terms of their insight and sophistication (Guba, 1992; Guba & Lincoln, 1994). When contextualised to the present study, a relativistic ontology was espoused by:

1. Considering the meanings which participants impart on MS-F as subjective meanings constructed by participants within their lived worlds.
2. Regarding participants' understandings of MS-F as subject to variation.
3. Recognising that participants' accounts of MS-F may differ in sophistication and insightfulness.

3.1.2 Transactional and Subjectivist Epistemology

I espoused a transactional and subjectivist epistemological stance in accordance with Guba and Lincoln (1994, 2005). A subjectivist stance was adopted by espousing notions inherent to my relativist ontology (i.e. subjective, and socially constructed realities), and by assuming that I could access knowledge through social interactions. Concurrently, I adopted a transactional stance by regarding knowledge generation as an interactive process in which my personal features (e.g. values and personhood) would inevitably influence the research findings. As such, knowledge generation itself was seen as the collaborative outcomes of researcher-participant interactions (Guba & Lincoln, 1994). I espoused a transactional and subjectivist epistemology by:

1. Assuming that participants' lived experiences of MS-F could be accessed through a researcher-participant interaction.
2. Regarding research findings as the co-created outcomes of a joint research venture between me and participants.

3.2 IPA as a Theoretical Orientation

I used IPA as a theoretical orientation to guide me in exploring PwMS's lived experiences of MS-F. IPA is a qualitative research approach that provides a theoretical grounding and analytical guide for the exploration of lived experiences (Brocki & Wearden, 2006). As a theoretical orientation, IPA is based on three theoretical foundations, namely, phenomenology, hermeneutics, and ideography (Larkin et al., 2006; Smith et al., 2009/2012a). It is through these theoretical foundations that IPA can guide an in-depth examination of how people make sense of experiences/phenomena (Smith, 2004; Smith & Osborn, 2015). Here these theoretical foundations guide the IPA researcher in exploring lived experiences by: (a) informing the research design and methodology (Smith et al., 2009/2012b), and (b) directing the process of data analysis (Brocki & Wearden, 2006; Smith et al., 2009/2012c). In the following subsections, I discuss IPA's theoretical influences and what they implied for this study.

3.2.1 Phenomenology

Phenomenology is a philosophical approach (Smith et al., 2009/2012a; Smith & Osborn, 2015) concerned with how people make sense of important/salient experiences in their lives (Smith et al., 2009/2012d). IPA is phenomenological in nature since it seeks to conduct an in-depth examination of lived experiences (Smith & Osborn, 2015) as perceived within participants' consciousness (Smith et al., 2009/2012a). That is, IPA aspires to identify and describe peoples' sense-making of an experience/phenomenon in terms of cognition (Biggerstaff & Thompson, 2008; Moodley, 2009; Smith et al., 2009/2012a).

Through its phenomenological grounding, IPA assumes that humans are sense-making beings who impart meaning(s) on their everyday experiences of events/situations/phenomena (Smith et al., 2009/2012a; Vicary, 2017). Moreover, IPA regards meaning as comprising our everyday perceptions/conceptions of phenomena – cognitions which reflect our preconceived expectations and beliefs (Goodall, 2014; Smith et al., 2009/2012a). In being phenomenological, IPA is anchored within a phenomenological continuum ranging from a descriptive to a more hermeneutic stance (Vicary, 2017). IPA's descriptive stance emphasises that the IPA researcher needs to disengage from their typical/everyday sense-making processes (i.e. their taken-for-granted sense-making) to understand phenomena as others understand them (Smith et al., 2009/2012a; Vicary, 2017). Here a descriptive phenomenological stance holds that by reflecting on how one perceives a phenomenon, one may bracket off these typical/everyday sense-making processes (Smith et al., 2009/2012). In theory, such reflection and bracketing would permit a phenomenologist to identify the essence (Larkin & Thompson, 2012) and universal meaning(s) of phenomena (Goodall, 2014). Nonetheless, given IPA's concomitant hermeneutic phenomenological stance, the act of identifying the very essence of phenomena is seen as improbable.

Hermeneutic phenomenology views individuals as imbedded within their lived worlds, and posits that a reciprocal relationship exists between individuals and their worlds (Smit et al., 2009/2012a). Moreover, hermeneutic phenomenology considers sense-making to be an interpretative act/process (Smit et al., 2009/2012a). Here people's sense-making of phenomena (i.e. their interpretations) are seen as mediated by the world and subject to pre-existing expectations, beliefs, and understandings (Vicary, 2017). As such, IPA's hermeneutic phenomenological stance suggests that the IPA researcher would never be able to fully bracket off their taken-for-granted sense-making processes. Moreover, IPA's hermeneutic phenomenological stance theorises that any exploration of lived experiences would constitute an interpretative act (Vicary, 2017). Consequently, IPA does not purport itself as capable of identifying the very essence of a phenomenon. Much rather, IPA suggests that a researcher may come close to this essence by being phenomenological in their interpretation of lived experiences.

When contextualised to research, IPA's phenomenological foundation designates bracketing as central to exploring lived experiences (Smith et al., 2009/2012a) in a considered and systematic manner (Goodall, 2014). As such, I vied to be phenomenological in exploring lived experiences by:

1. Approaching participants' lived accounts of MS-F in a receptive and non-judgmental manner.
2. Critically and continuously reflecting on my understanding and interpretations of how PwMS understood MS-F as a FOL. I did this to become cognisant of, and attempt to put aside, my assumptions, expectations, knowledge, experiences, and preconceived notions of what living with MS-F signified.

Nonetheless, in line with IPA’s hermeneutic phenomenological stance, I regarded myself as incapable of fully bracketing off my taken-for-granted sense-making. For a more detailed account of being phenomenological during data analysis see section 4.5.

3.2.2 Hermeneutics

Hermeneutics refers to the theory of interpretation (Smith et al., 2009/2012a) and is the second theoretical cornerstone of IPA (Larkin et al., 2006; Smith, 2004). IPA is an approach which designates a phenomenological venture to be a hermeneutic endeavour (Smit et al., 2009/2012a). Here IPA holds that meaning(s) and sense-making can only be accessed and described through an interpretative act/process (Biggerstaff & Thompson, 2008; Larkin & Thompson, 2012). As such, the researcher is regarded as central to elucidating and identifying lived experiences (Biggerstaff & Thompson, 2008; Smith et al., 2009/2012a). In this section, I discuss hermeneutics as it informed the present exploration of lived experiences.

Heidegger (1926/2019) designated phenomenology as interpretative in nature (Smith et al., 2009/2012a) since humans are sense-making creatures (Smith & Osborn, 2015). He highlights that the meaning of experiences exists within accounts/text as overt meanings (possibly deceptive) which are intimately linked to latent meanings (i.e. concealed/hidden meanings) (Smith et al., 2009/2012a). Here Heidegger (1926/2019) suggests that analytical engagement with experiential accounts may facilitate the appearance of latent meanings and permits one to identify sense-making processes (Smith et al., 2009/2012a). Accordingly, IPA theorises that an in-depth interpretative analysis of experiential data may yield insights into the meanings and sense-making of phenomena (Smith et al., 2009/2012a). Building on this, Schleiermacher (1998) highlights that meaning(s) may be examined by interpreting: (a) linguistic elements to understand the authors account, and (b) psychological elements to come to an understanding of the author of the account (Smith et al., 2009/2012a). IPA adopts these emphases thereby permitting researchers to interpret meanings in a manner that subsumes yet expands on participants’ literal accounts (Smith et al., 2009/2012a). When contextualised to the present research, hermeneutics suggest that PwMS’s lived experiences of MS-F may be explored by: (a) interpreting the meaning of participants' literal accounts of living with MS-F, and (b) by interpreting what participant sought to convey through their accounts.

In IPA, the interpretative process constitutes a double hermeneutic since the researcher is trying to make sense of how a participant makes sense of their experience (Smith & Osborn, 2015). Here interpretation is – to some degree – rooted in a researcher's fore conceptions (Smith et al., 2009/2012a). To interpret lived experiences more accurately, the IPA researcher must actively reflect on their interpretations (i.e. their understanding of experiential accounts) (Smith et al., 2009/2012a). Such active reflection may permit the IPA researcher to identify, and bracket off, those fore conceptions which unduly affect interpretations (Smith et al., 2009/2012a). As such, interpretation in IPA follows a dynamic and cyclical process referred to as the hermeneutic circle (Smith et al., 2009/2012a). Based on Vicary (2017) and Smith et al. (2009a), I constructed a visual depiction of the hermeneutic circle in Figure 3.1 below.

Figure 3.1

The Hermeneutic Circle in IPA

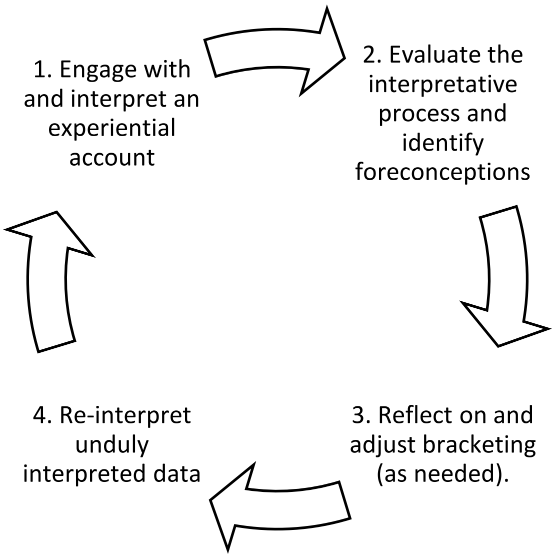

Figure 3.1 Visual representation of the hermeneutic circle characterising the double hermeneutic interpretative process in IPA.

As illustrated in Figure 3.1, cyclical iterations of interpretation are accompanied by cyclical iterations of reflection within the hermeneutic circle. The cyclical iterations of reflection are important since they assist the researcher to interpret lived experiences more accurately (Smith et al., 2009/2012a). Concurrently, recurrent iterations of interpretation refine interpretations to more accurately represent/reflect participants' lived experiences (Smith et al., 2009/2012c). As such, the hermeneutic circle was central to data analysis and reflection in this study (see section 4.4).

3.2.3 Ideography

IPA's last theoretical foundation is an ideographic commitment (Vicary, 2017) which amounts to a commitment to particularity (Larkin & Thompson, 2012; Smith et al., 2009/2012a). For IPA, this ideographic commitment is expressed at two levels (Smith et al., 2009/2012a). Firstly, IPA is committed to coming to an understanding of experiences as understood by specific participants within their particular contexts (Larkin & Thompson, 2012; Smith et al., 2009/2012a). Concurrently, IPA is also committed to particularity by seeking an in-depth analysis of idiosyncratic lived experiences (Smith et al., 2009/2012a). Contextualised to this study, an ideographic commitment meant that I sought to interpret how each participant understood their idiosyncratic MS-F experiences within their respective contexts.

Importantly, IPA's ideographic commitment allows the IPA researcher to use case specific lived experiences to make more general statements about lived experiences (Smith & Osborn, 2015). Here IPA does not regard the particular and general as distinct (Smith et al., 2009/2012a). Much rather, IPA echoes Herman's (1988) statement that: "The particular eternally underlies the general; the general eternally has to comply with the particular" (p. 785). Thus, IPA considers insight into specific meanings as providing insight into more universal meanings (Smith et al., 2009/2012a). In theory, this means that by exploring an individual's lived experiences of a phenomenon; the IPA researcher may come to identify the more universal meaning of that phenomenon. Nonetheless, IPA does not aim to generalise a particular insight/meaning to other populations (Vicary, 2017). Much rather, IPA seeks to examine the particular to identify an understanding which may, or may not, be shared by others (Smith et al., 2009/2012a; Vicary, 2017). Accordingly, whilst IPA seeks to identify more universal meanings and sense-making processes; it does not regard these meanings and sense-making patterns as representative of how others will understand a phenomenon/experience.

3.3 Experience as a Concept in IPA

Thus far I have assumed that the term "experience" is a commonly understood concept with a ubiquitous meaning. This is, however, not the case. In IPA, experiences are regarded as hierarchical and IPA itself is concerned with a specific type of experience in this hierarchy (Smith et al., 2009/2012d). The notion that experiences are hierarchical is rooted in Dilthey's (1976) work which emphasises that an experience encompasses different levels of experience (Vicary, 2017). According to Dilthey (1976):

> Whatever presents itself as a unit in the flow of time because it has a unitary meaning, is the smallest unit which can be called an experience. Any more comprehensive unit which is made up of parts of a life, linked by a common meaning, is also called an experience, even when the parts are separated by interrupting events. (p. 210)

Thus, at its most elemental level, experience refers the everyday FOL which people are continuously and unselfconsciously caught up in (Smith et al., 2009/2012d). For example, when contextualised to this study, experience refers to "a/the experience" of being/feeling fatigued (i.e. the explicit experience). However, as a person reflects on the significance of a salient experience (e.g. a major event/situation/change) they start to become aware of: (a) what is happening to them, and (b) the implications of the experience (Smith et al., 2009/2012a). That is, they start making sense of the salient experience by coming to an understanding of it and its implications for life (Smith et al., 2009/2012a). Through this sense-making, "a/the experience" of something becomes "an experience" of something (i.e. a more comprehensive experience) where the affected areas of life have a common meaning (Smith et al., 2009/2012a). For example, PwMS reflecting on their fatigue experiences may regard MS-F as a lack of energy which inhibits movement, restricts socialisation, and restricts volitional action. In this example, the impacts of MS-F (i.e. "a/the experiences") are linked by a shared notion of functional restriction (i.e. "an experience") which is more diffusely applicable within life. In essence, IPA focuses on such more comprehensive experiences and seeks to elucidate and examine their underlying meanings (Smith et al., 2009d). I regarded these more comprehensive MS-F related experiences as comprising PwMS's "lived experiences" of MS-F. Accordingly, through IPA, I sought to explore those shared meanings which underlay such more comprehensive experiences of MS-F.

3.4 Rationale for IPA as a Theoretical Orientation

I used IPA as a theoretical orientation to guide me in exploring PwMS's lived experiences of MS-F because of three reasons. Firstly, IPA's concern with coming to an understanding of lived experience is well suited to answering the RQ of the present study. Secondly, IPA's theoretical foundation is philosophically congruent with my ontological and epistemological assumptions. Lastly, IPA is well suited to examining how people understand complex and ambiguous phenomena (Smith & Osborn, 2015) such as MS-F. Taken together, it appeared that IPA was well-suited to facilitating an exploration of how PwMS in the WC understood MS-F as a FOL.

3.5 Critiques of IPA

IPA has been met with some critique and contention (Dennison, 2019). Some researchers have asserted that IPA is unscientific since it lacks a clear/rigid analytic method (Giorgi, 2011; Sousa, 2008). Additionally, Sullivan (2014) suggests that IPA is a promiscuous and reckless approach to data analysis. Whilst these criticisms are not baseless, they may be overstated. According to Dennison (2019), since IPA is predicated on interpretative processes, the expectation that IPA follows a fixed analytic process is misguided. Furthermore, whilst Sullivan (2014) may assert that IPA is promiscuous and reckless; IPA is guided through a distinctive theoretical orientation (Dennison, 2019). Moreover, IPA's theoretical orientation also delineates the analyst's ability and limitations in exploring lived experiences (see section 3.2). Accordingly, it appears that current critiques of IPA may emanate from either, or both:

1. Some critics misunderstanding the theoretical foundations of IPA. This assertion is consistent with Smith's (2018) response to criticism of IPA.

2. Some researchers misunderstanding the theoretical foundations of IPA. This assertion converges with van Manen’s (2017) concerns on phenomenological research.

It is debatable which of the above listed instances are most to blame for fuelling scepticism of IPA research. Nonetheless, in either instance, it is not IPA itself which appears to be the issue.

3.6 Conclusion

In this chapter, I highlighted constructivism as the research paradigm I adopted in exploring PwMS’s lived experiences of MS-F. This worldview was discussed in terms of the ontological and epistemological assumptions inherent to the present research study. Additionally, the implications of these philosophical stances for this study were also highlighted and described. Furthermore, I presented IPA as a relevant and appropriate theoretical orientation capable of guiding me in an exploration of PwMS’s lived experiences of MS-F. I presented and discussed the philosophical cornerstones which comprised IPA as a theoretical orientation (i.e. phenomenology, hermeneutics, and ideography). Additionally, I also alluded to what these philosophical stances implied for the present research study. Moreover, I differentiated “experience” from “lived experiences” and designated how IPA is concerned with identifying the shared meanings of those more comprehensive experiences of phenomena. In its totality, this chapter laid bare those philosophical and theoretical informants which characterised the research design, methodology, and data analysis.

Chapter 4: Research Design and Methodology

In this chapter, I discuss the research design and research methods employed to achieve the study's aim and objectives. As noted in Chapter 1, this study sought to answer the RQ: "What are the perceptions and meanings of living with MS-F amongst PwMS in the WC?" As such, the primary aim of the study was to explore and interpret how PwMS in the WC perceive and make sense of living with MS-F. To achieve this aim, I focused on attaining four objectives. These objectives were:

1. To explore and interpret accounts of MS-F as a symptomatic experience.
2. To explore and interpret accounts of how MS-F impacts daily life.
3. To explore and interpret accounts of how PwMS manage MS-F.
4. To explore and interpret accounts of how PwMS cope with MS-F.

I start this chapter by outlining my research design as an exploratory and cross-sectional research design with a phenomenological approach to inquiry. Thereafter, I present my approach to sampling and recruitment. This includes a discussion of the sampling strategy (i.e. purposive sampling) and sampling procedure implemented in the present study. Following this, data collection is described as involving the collection of both narrative data on living with MS-F, as well as circumstantial information (i.e. biographical, and clinical information) through measurement instruments. Hereafter, I present IPA analysis as the data analytic method used to explore participants' lived experiences of MS-F. In presenting IPA as my data analysis method, I highlight in detail the data analytic "steps" used to analyse participants' lived accounts of MS-F. Subsequently, I discuss my approach to reflexivity and bracketing followed by an overview of my ethical considerations in conducting this study. Finally, and prior to concluding this chapter, I discuss how I enhanced the trustworthiness of the present study's research findings.

4.1 Research Design

The three main components which comprised this study's research design were: (a) an exploratory design, (b) a cross-sectional approach to data collection, and (c) a phenomenological strategy to inquiry. As this subsection will illustrate, the selection of these design composites was informed by how best to answer the RQ within resource constraints.

4.1.1 Qualitative Approach: An Exploratory Design

A qualitative approach is characterised by inquiry seeking to explore and understand the meanings social entities impart on phenomena within their natural settings (Creswell, 2014b; Bless et al., 2014a). In attaining its purpose, qualitative research employs an inductive approach to enquiry (Bryman, 2012a), focusses on meanings and experiences (Creswell, 2014b; Willig, 2001), and underscores the complexity of the phenomena under investigation (Creswell, 2014a). Here qualitative research facilitates the development of more holistic understandings which are not intended to be generalisable (Bryman, 2012b; Creswell, 2014b). Moreover, qualitative research generates a more ideographic understanding of what it means for people to live with a phenomenon within a certain social context (Bryman, 2003/1998). Consequently, it was evident that a qualitative approach would be well suited to exploring PwMS's lived experiences of MS-F.

Exploratory research designs, such as the one adopted in this study, are deeply entrenched within a qualitative approach to enquiry. Here this design was deemed to be appropriate given its ability to elucidate the breadth and scope of a particular topic of inquiry (Bless, 2014b). That is, an exploratory design provided a means by which to redress the relative lack of knowledge on PwMS's lived experiences of MS-F. Notably, the selection of an exploratory design represented an important methodological informant which allowed for the research process to: (a) be refined with respect to the demands of the RQ, and (b) be characterised by an implicit cognisance of the research rationale.

4.1.2 Cross-sectional Data Collection

The present study adopted a cross-sectional approach to data collection where data were sampled from participants at a single point in time. The choice of a cross-sectional approach to data collection denoted my attempt to find a pragmatic balance between answering the RQ and conducting the research within my resource constraints (i.e. time and financial constraints). Cross-sectional data collection is a relatively quick and inexpensive process (Bryman, 2012c; Sedgwick,

2014) by which to collect multiple data sets (Bryman, 2012c), and provided a realistic way to conduct the present study within resource constraints.

4.1.3 Phenomenological Strategy to Inquiry

The exploratory research design was guided by a phenomenological strategy to inquiry. The selection of this approach was, in line with Creswell et al.'s (2007) recommendations, largely informed by the nature of the RQ. The RQ is an essence question (i.e. a question concerning the quintessence of what individuals experience) which designates a phenomenological strategy to inquiry as the most appropriate approach (Morse & Field, 1996). Moreover, Creswell et al. (2007) highlights that an exploration of lived experiences is best achieved through phenomenological inquiry. Accordingly, I adopted a phenomenological strategy to inquiry in this research study.

4.2 Sampling and Recruitment of Participants

4.2.1 Sampling Strategy: Purposive Sampling

I used purposive sampling to recruit PwMS who live in the WC and suffer from self-reported moderate/severe fatigue. I implemented this non-probability sampling technique since it permitted a more flexible approach to recruitment when compared to probability sampling techniques (Bless et al., 2014a). Purposive sampling allowed me to develop inclusion criteria which ensured that I recruited: (a) a sample of relevant participants, and (b) MS-F cases unaffected by either a current/recent relapse or a recent MS diagnosis. In this way, purposive sampling enhanced data quality prior to data analysis.

The sample inclusion criteria (See Table 4.1 on the next page) comprised two sets of criteria (i.e. relevance criteria and data quality control criteria). These criteria represented my informed, yet subjective, conclusions of what constituted a relevant and less confounding case of MS-F. All prospective participants (i.e. individuals interested in participating in the study) needed to meet these criteria to be eligible to participate in the study. Those individuals who did not meet these criteria were excluded from the research.

Table 4.1

Sample Inclusion Criteria Defining Eligibility to Participate

Sample Inclusion Criteria	Sample Exclusion Criteria
Relevance Criteria	Irrelevance Criteria
Being older than 18 years of age	Being younger than 18 years of age
WC resident	Non-WC resident
Medically confirmed MS diagnosis	Non-medically confirmed MS diagnosis
Self-reported moderate/severe fatigue	Self-reported mild/no fatigue
Data Quality Control Criteria	Data Quality Forgoing Criteria
Not being in the post-diagnosis crisis phase	Being in the post-diagnosis crisis phase
Absence of a current/recent MS-related relapse	Presence of a current/recent MS-related relapse

The data quality control criteria required that participants could not be in the post-diagnosis crisis stage or have had a current/recent MS-related relapse. The post-diagnosis crisis phase was considered, akin to Stuifbergen and Rogers (1997), as persisting for one year after individuals were diagnosed with MS. Whilst a recent MS-related relapse was considered, in accordance with Powell et al. (2017), to be a self-reported relapse which occurred within the last three months. These criteria increased data quality by excluding confounding features which could have influenced the research findings. I could not exclude cases presenting with any additional confounding features (e.g. depression or sleep apnea) since MS-F's complex aetiology would have made it difficult to find eligible participants and attain sample size goals. Nevertheless, I do describe participants in relation to various potentially confounding features (this is discussed later). Crucially, neither disease subtype nor severity were deemed appropriate inclusion/exclusion criteria. Disease severity was deemed inappropriate since the subjective experience of MS-F does not consistently correlate with any objective physical signs, other MS-related symptoms, or neurological impairment (Ayache & Chalah, 2017; Leocani et al., 2008). Furthermore, MS subtypes were disregarded as inclusion/exclusion criteria since MS-F may develop within all MS subtypes (Krupp et al., 2010).

4.2.2 Sampling Procedure

There is no right answer to sample size for IPA studies (Smith et al., 2009/2012b) which typically recruit between one and 15 participants (Pietkiewicz & Smith, 2014). Nevertheless, since IPA analyses are concerned with detailed accounts of idiosyncratic experiences (i.e. quality and not quantity) (Smith et al., 2009/2012a), smaller sample sizes are preferred (Smith et al., 2009/2012b; Pietkiewicz & Smith, 2014). Here Smith et al. (2009/2012b) highlights that a sample of three to six participants would be sufficient for a master's level IPA study.

I recruited participants on a first-contact-first-recruit basis and sampled until data saturation was reached at the descriptive level of narratives. In accordance with Fusch and Lawrence (2015), I considered data saturation to be the point at which further interviews generated no new data. Multiple Sclerosis South Africa (MSSA) (Maxitec Internet & Cellular, 2015) assisted me in sampling participants in the present study. The director of MSSA's WC branch, Non Smit, facilitated sampling by posting a participatory invitation in the form of a flyer (See Appendix A) on the MSSA's Facebook page. Upon being contacted by prospective participants, I scheduled a date and time for me to call them to complete a screening questionnaire (See subsection 4.3.1.1). This questionnaire established the eligibility of prospective participants relative to the inclusion criteria. Prospective participants who met the inclusion criteria were formally invited to partake in the study. Sampling was initiated on the 7th of November 2018 by the flyer being uploaded to MSSA's Facebook page, two of its forums, and a closed online support group. Additionally, I requested that the flyer be uploaded a second time on the 30th of January 2019. Recruited participants partook in individual, semi-structured interviews (see subsection 4.3.2), and completed a post interview battery of instruments (see subsection 4.3.1.2). Recruitment and the primary data collection phase was concluded on the 4th of March 2019.

Following data collection, I reviewed the content of each narrative in terms of its sophistication. I did this because IPA requires a rich data set to be performed (Smith et al., 2009/2012e). I regarded a sophisticated narrative to be a data thick and data rich account.

According to Fusch and Lawrence (2015), a data rich narrative is a deep, complex, intricate, and multi-layered account (i.e. a high-quality account); whilst a data thick narrative is an account characterised by a broad scope of data. Through a subjective evaluation process (see section 5.1), I selected the six most rich and thick narratives for subsequent analysis. I selected narratives in this way to ensure that the final sample consisted of accounts well suited for IPA analysis.

Notably, whilst processing data, I identified that most participants reported to be suffering from depression. Given this, I resolved to conduct audio-recorded follow-up interviews with these participants. These interviews were conducted with the intent of clarifying whether participants could distinguish MS-F from fatigue in depression (see subsection 4.3.2). This second data collection phase was initiated on the 3rd of May 2019 and concluded on the 13th of May 2019.

4.2.3 Sampling Population: The MSSA's Facebook Page

The MSSA is a prominent non-profit organisation and authority on MS in South Africa with branches in the WC, Gauteng, and Kwa-Zulu Natal (Maxitec Internet & Cellular, 2015). They provide support and information to PwMS, and promote an awareness of MS across SA (MSSA, 2018). The MSSA has developed a strong online presence with ± 1,900 PwMS throughout SA following their Facebook page. By sampling from this geographically dispersed population, I could broaden recruitment across the WC which allowed me to document lived experiences across the broader WC context. I decided to do this since sampling through an HCP would have centred participants and their lived experiences around a single geographical area, something that would have excluded PwMS living further away from HCP's or who lived in the more rural areas of the WC. Such a geographical constriction was undesirable since it could have: (a) decreased the variability of experiential narratives, and/or (b) distorted how PwMS living in the WC understood MS-F as a FOL. Nonetheless, I acknowledge that sampling through an HCP could have increased sample homogeneity. Such increased homogeneity would have enhanced the trustworthiness of the present IPA research study (Smith et al., 2009/2012d).

4.3 Data Collection

I collected data from participants by administering measurement instruments and by conducting semi-structured interviews. The data collected through semi-structured interviews were central to answering the RQ, and hence, was the primary focus of subsequent analyses. In contrast, data collected through measurement instruments were not explicitly relevant to answering the RQ. Much rather, this data was essential for purposive sampling and provided circumstantial data relevant to the study (i.e. was indirectly relevant to answering the RQ). I discuss what data collection entailed in the present study through the ensuing subsections.

4.3.1 Measurement Instruments

The measurement instruments that were used in this study included a screening questionnaire and post-interview battery of instruments. The present study collected questionnaire data to: (a) facilitate the purposive sampling process, (b) describe the sample's characteristics, and (c) better contextualise participants' accounts of living with MS-F.

4.3.1.1 Pre-interview Screening Questionnaire. As mentioned earlier, prospective participants were asked to complete a telephonic screening questionnaire (See Appendix B). The five-minute screening questionnaire consisted of 7 items and determined the eligibility of the prospective participants to participate in this study. In line with the inclusion criteria previously highlighted, the questionnaire collected some preliminary demographical data on participants' age and geographical location. Furthermore, preliminary clinical data was also collected by this questionnaire. Data was collected on whether participants had been medically diagnosed with MS to ensure that the research occurred in the context of MS. Additionally, data was collected on how long (in years) participants have lived with a medical diagnosis of MS to ensure that participants were not in the post-diagnosis crisis period. Moreover, data on how PwMS self-reported their MS-F severity was collected to gauge MS-F's salience, and hence, "caseness". Finally, data on whether participants had a current/recent MS-related relapse was collected to ensure that MS-F's severity and experience was not confounded by said events.

4.3.1.2 Post-interview Battery of Instruments. The post-interview battery of instruments was completed by participants immediately following the telephonic interviews and took approximately 20 minutes to complete. This battery consisted of a biographical questionnaire, the Patient-determined Disease Steps (PDDS), and the Chalder Fatigue Scale (CFQ).

4.3.1.2.1 Biographical Questionnaire. The biographical questionnaire (See Appendix C) collected demographic data on participants' gender, race, home language, current living situation, marital status, education level, socio-economic and employment status. Demographic data was primarily used to describe the sample's composition and features. Nonetheless, such data was also used to contextualise experiential narratives of MS-F in a more ideographic manner during IPA analyses. The data collected on race was self-identified and used solely for descriptive purposes. Nonetheless, I am aware of the controversy surrounding the use of racial categories as descriptive features (particularly given SA's socio-historical context). Consequently, I was committed to being sensitive and cognisant in how I used this data.

The biographical questionnaire also collected clinical information on participants' age of MS onset and their MS subtypes to better describe the sample. Additionally, data on whether participants have been diagnosed with other clinical conditions besides MS (i.e. neurological conditions, psychosocial disabilities, and/or other major health conditions) was also collected. The collection of this data was essential to data quality by embodying a cognisance of the multifaceted aetiology of MS-F. Here this data allowed me to identify potential overlap and confounding between MS-F and fatigue that emanated from other sources.

4.3.1.2.2 Patient-determined Disease Steps. The PDDS (See Appendix D) is a self-report measure of disease severity which assesses functional disability status. It was developed by researchers associated with the Patient Registry of the North American Research Committee on MS (NARCOMS) (Rizzo et al., 2004) as a self-report version of the physician administered Disease Steps – a measure of MS-related functional disability (Hohol et al., 1999; Hohol et al., 1995).

Within the PDDS, 9 mobility scenarios, as ordinal levels ranging from 0 (Normal) to 8 (Bedridden), are presented to participants who then select the scenario which most accurately reflects their degree of mobility impairment (Hohol et al., 1995; Schwartz et al., 1999). These functional disability scores may then: (a) be used as categorical estimates of disability level (Buchanan et al., 2010; Hohol et al., 1999; Taylor et al., 2014), (b) be converted into Expanded Disability Status Scale (EDSS) scores (Kobelt et al., 2006), or (c) be used to classify individuals as suffering from mild, moderate, or severe disability (Marrie et al., 2006). In the present study, I used PDSS scores to describe participants' disability status as mild, moderate, or severe.

Whilst the PDDS has been broadly utilised in MS-related research (Learmonth et al., 2013) in the USA (Hadjimichael et al., 2008; Kobelt et al., 2006; Lo et al., 2005; Marrie & Goldman, 2007; Rizzo et al., 2004; Sasaki et al., 2018); thus far it has not been administered within either an African or South African context. Nevertheless, amongst clinic attending MS patients in the USA, the PDDS has demonstrated criterion validity through a strong correlation (ρ = .783) between PDDS scores and clinician-administered EDSS scores (Learmonth et al., 2013). Moreover, the PDDS is a self-report measure that doesn't require experienced clinicians to score disability level – such as with the EDSS (Kurtzke, 1983). Consequently, the PDDS provided a quick, simple, and economic means for describing the disease severity of participants.

4.3.1.2.3 Chalder Fatigue Scale. The CFQ (See Appendix E) is a simple and brief self-rating scale (taking 2 – 3 minutes to complete) (Braley & Chervin, 2010) that is capable of measuring fatigue severity (Cella & Chalder, 2010; Chalder et al., 1993). It was developed by Chalder et al. (1993) in the UK with the intent of measuring fatigue severity amongst hospital and community populations. In line with this, the CFQ has been widely administered to quantify fatigue severity in a variety of non-clinical and clinical samples (Cella & Chalder, 2010; Jackson, 2015) including MS (Moss-Morris et al., 2012; Skerrett & Moss-Morris, 2006; van Kessel et al., 2008).

The CFQ consists of 11 items covering two domains, physical fatigue (measured by items 1 – 7) and mental fatigue (measured by items 8 – 11). Each item requires respondents to rate the frequency of their fatigue-related symptoms by selecting one of four response options (Cella & Chalder, 2010) which range from asymptomatic to maximum symptomatology (Jackson, 2015). I scored the CFQ by using a bimodal type scoring system in which the first two response options were scored as 0 and the last two were scored as 1. Subsequently, scale total scores (ranging from 0 – 11) were calculated by summing all item response scores. In accordance with administrative guidelines (Chalder et al., 1993; Jackson, 2015), and research conducted on MS-F sufferers (Moss-Morris et al., 2012), a score greater than four indicated significant fatigue severity. Nevertheless, CFQ scores were used purely for descriptive purposes and not as an inclusion criterion. As mentioned previously, self-reported MS-F severity determined the eligibility of prospective participants to participate in this study.

The CFQ has demonstrated reliability within the UK through Cronbach Alphas of .92 within a sample of chronic fatigue syndrome patients ($N = 361$) and .88 within a general practice attender sample ($N = 1615$) (Cella & Chalder, 2010). Similar internal consistencies (i.e. $\alpha > .86$) and the replication of the CFQ's two-factor structure has also been observed amongst 304 primary health care attenders in Brazil (Cho et al., 2007) and 201 Chinese adults (Wong & Fielding, 2010). Furthermore, Coetzee et al. (2018) found that the CFQ possessed a high internal consistency ($\alpha = .83$) among HIV positive South African adolescents ($N = 134$) receiving anti-retroviral therapy. Moreover, Chilcot et al. (2016) determined that the CFQ is a psychometrically sound measure of fatigue severity amongst PwMS. Considering these findings, it appeared that the CFQ would be an appropriate measure by which to describe participants' MS-F severity.

4.3.2 Semi-structured Interviews

I collected narratives of PwMS's lived experiences of MS-F by conducting individual semi-structured interviews with participants. I conducted in-depth interviews since communication constitutes a sense-making process (Seidman, 2006). Moreover, interviews are well suited to generating rich and detailed experiential accounts (a prerequisite for IPA) and can elucidate meanings and sense-making processes (Smith et al., 2009/2012e). I conducted semi-structured interviews by following a self-designed interview guide (See Appendix F). By being flexible during the interview process, I could: (a) explore salient topics as they arose, and (b) explore in greater depth the meanings elicited during the interview process.

4.3.2.1 Interview Method, Modality, and Language. I conducted individual interviews since this method of interviewing is well suited to eliciting experiential narratives and minimises the risk linked to participation (Smith et al., 2009/2012e). All interviews were conducted telephonically as this interview modality was quicker and cheaper than conducting face-to-face interviews (Bryman, 2012d; Weiten, 2016). These advantages were particularly salient since participants were recruited throughout the WC and, as such, were geographically dispersed. Nevertheless, I acknowledge that there are certain limitations to telephonic interviews which may include, but are not limited to: (a) the systematic exclusion of participants who do not have landlines/cell phones, (b) a reduced ability to detect non-verbal cues (e.g. confusion or discomfort) when compared to face-to-face interviews, (c) potential technical difficulties (e.g. poor cellular reception) (Bryman, 2012d), (d) a frustrated rapport building process, and/or (e) being perceived as intrusive (Weinten, 2016). The risks linked to a reduced ability to detect non-verbal cues via the telephone was mitigated, in part, through the counselling skills training I received from Lifeline (a nationwide telephonic counselling service provider). Concurrently, I used the pre-screening interview and research-related correspondence as opportunities to build rapport with participants prior to interviews. Notably, in anticipation of participants being uncomfortable with a telephonic interview modality, I proposed a Skype or at home face-to-face interview (provided the participant lived within a ±50 km drive from Stellenbosch) as possible alternatives. Nonetheless, no participants made use of these interview modalities and they communicated their comfortability with partaking in a telephonic interview.

Interviews were conducted exclusively in English with both first and second language speakers. Whilst this excluded all non-English speakers’ accounts of living with MS-F, it was essential to ensuring data quality. The translation of experiential narratives from other South

African languages into English, whilst yielding a literal translation, would not accurately reflect the understandings communicated. Much rather, a translator's understanding would be imposed on translated narratives generating unintended semantic artefacts which could distort the research findings (van Nes et al., 2010). Since IPA seeks to explore perceptions and sense-making, it would be sensitive to the semantic errors that may arise through translation.

4.3.2.2 Interview Guide. The interview guide I used during the interviews included introductory questions, as well as questions on MS-F's symptomatic experience, MS-F's impact on daily life, MS-F management, and coping with MS-F. The introductory questions were intended to be broad and to encourage participants to talk whilst collecting some data. All other questions were more specific in that they were directly aligned with the research objectives.

I developed an initial draft of the interview guide by noting down questions, and several probes, which inquired about MS-F as a FOL. The questions and probes within the initial interview guide were devised based on: (a) existing literature on how PwMS and PwoCCs understand fatigue, (b) literature on how to construct an interview guide for IPA (Smith et al 2009/2012e), and (c) the research aim and objectives. The initial draft of the interview guide was subjected to two rounds of refinement based on the guidance and advice I received from my supervisor. These two rounds of refinement led to several revisions. Such revisions included the removal, addition, and rewording of questions and probes which were leading, loaded, or overly abstract. Following this revision process, a third draft of the interview guide was piloted during the first two interviews. Here piloting suggested that some minor alterations were needed alongside opening and closing statements. After responding to these issues, the interview guide was amended into its fourth and final form which consisted of eight questions (See Appendix F).

The interview guide used during the follow-up interviews was constructed through guidance received from my supervisor. This interview guide was developed to clarify whether participants could distinguish MS-F from fatigue in depression. The final format of the follow-up interview guide consisted of three questions (See Appendix G).

4.3.2.3 Collecting Experiential Data. I conducted interviews with participants who met the inclusion criteria and ratified their willingness to participate by emailing me a signed informed consent form. Interviews were scheduled and conducted at pre-scheduled dates and times which suited me and the participants. Throughout the interview process, I flexibly followed the interview guide. Interviews took between 30 minutes and 60 minutes to be completed (50.52 minutes on average). All interviews were audio-recorded with the intent of being transcribed by a professional transcriptionist for subsequent analysis. Crucially, I conducted the interviews prior to administering the post-interview battery of instruments. This was done to prevent suggestive/leading/loaded items in the biographical questionnaire, PDDS, and CFQ from influencing participants' accounts of living with MS-F. I continued to interview new participants until data saturation was reached at content level whereafter I selected the six most rich and sophisticated narratives as cases to be analysed. Follow-up interviews were conducted to generate data capable of supplementing the primary data set. These follow-up interviews took 14.58 minutes on average to complete. This data was also audio recorded and subsequently transcribed by me. I analysed this data to clarify whether the present study's research findings could have been distorted by depression-related fatigue.

4.3.2.4 Transcription. Each interview was transcribed verbatim along with certain linguistic features (e.g. utterances) in accordance with the explicit written instructions I provided to the transcriptionist. To ensure consistency and transparency throughout the transcription process, these instructions were accompanied by a transcription convention (See Appendix H). I constructed this convention by drawing from existing transcription systems (Chadwick, 2014; De Fina & Georgakopoulou, 2012; Jefferson, 2004; Sidnell, 2011) such that only IPA relevant linguistic features would be transcribed. Here the convention's specifications converged with IPA's primary aim of interpreting the meaning of narrative content – something which does not require the transcription of all linguistic features (Smith et al., 2009/2012e).

4.4 Data Analysis

I conducted an IPA analysis of participants' experiential accounts of living with MS-F. I analysed participants' lived experiences of MS-F by implementing a data analysis procedure within an over-arching data analysis strategy. Here the data analysis strategy provided me with a framework within which I could situate my approach to data analysis. The data analytic procedure comprised a set of analytic steps which I followed to interpret participants' perceptions and understandings of MS-F. Notably, I systematically lessened a rigid adherence to these steps as the analysis proceeded and I became more familiar with IPA and its philosophical cornerstones.

4.4.1 Data Analysis Strategy

IPA analysis is an indicative and iterative data analysis approach (Reid et al., 2005) which proceeds by drawing on various strategies (Smith et al., 2009/2012c). As such, there is no one right way of doing an IPA analysis (Smith et al., 2009/2012c). Much rather, IPA analysis involves the iterative and cyclical implementation of various processes and principles in a flexible and responsive manner (Smith et al., 2009/2012c). Since this research represented my first IPA study, I used IPA's data analysis strategies (See Appendix I) as a framework within which my data analysis procedure was embedded.

4.4.2 Preparing Data for Analysis

Before analysing data, I reviewed the consistency of interview transcripts relative to their audio recordings. I did this to confirm the accuracy of the transcription process and to correct transcriptional errors/oversights. Hereafter, each transcript was imported into a table in Microsoft Word that was suitable for IPA analysis (See Appendix J). Subsequently, IPA analysis commenced according to the data analytic procedure described in the next section.

4.4.3 Data Analysis Procedure

Smith et al. (2009/2012c) recommends that a novice IPA researcher follow their proposed steps for conducting an IPA analysis. These steps, whilst presented as a unidirectional guide, cannot be compared to the steps of a recipe (Smith et al., 2009/2012c). Much rather, each step offers a different lens through which to flexibly approach and think about the data. As such, Smith et al.'s (2009/2012c) steps provide a structure for the IPA analytic process which is intended to be flexible. Since the present research study was my first IPA study, I decided to work closely with Smith et al.'s (2009/2012c) data analysis steps. These steps were:

1. Reading and re-reading
2. Initial Noting
3. Developing emergent themes
4. Searching for connections across emergent themes
5. Moving to the next case
6. Looking for patterns across cases

As I became more experienced with IPA's analytic approach and theoretical foundations, I later implemented Smith et al.'s (2009/2012c) steps in a more flexible and non-sequential manner. Notably, in line with IPA's ideographic commitment, I conducted and completed a detailed analysis of a single transcript in isolation before analysing other transcripts. I provide a detailed description of the steps I used to explore participants' lived experiences of MS-F in the following subsections.

4.4.3.1 Step 1: Reading and Re-reading. The first step of IPA analysis entails one immersing oneself within the original data (Smith et al., 2009/2012c). I did this by reading a participant's interview transcripts whereafter I listened to the relevant audio-recorded interview. Thereafter, I continued reading and re-reading the transcript all the while imagining the voice of the participant as I continued. According to Smith et al. (2009/2012c), such an imaginative approach may facilitate a more comprehensive IPA analysis. The reading and re-reading step was conducted to ensure that the participant becomes the focus of the analysis (Smith et al., 2009/2012c). Here repeated iterations of reading served to slow down the human propensity for automatically summarising complex information (Smith et al., 2009/2012c). As such, through repeated reading, I became more aware of aspects in myself that needed to be bracketed off. Such aspects which I identified and attempted to bracket off were:

1. My most salient recollections of an interview with a participant.
2. My most salient observations, impressions, and thoughts after reading a transcript.
3. Overwhelming ideas and thoughts I had as I read a transcript for the first time.

4. My preconceptions (see subsection 4.5).

The process of bracketing was facilitated by noting the above realisations and insights in case-specific electronic notebooks.

4.4.3.2 Step 2: Initial Noting. During exploratory commenting, the analyst tentatively interprets semantic content and language within the transcript. Here the aim is to generate a comprehensive and detailed set of tentative comments that is closely linked to narrative data (Smith et al., 2009/2012c). To do this I [in accordance with Smith et al.'s (2009/2012c) recommendations] approached the transcript in a receptive manner and made comments of everything of interest. I conducted a close line-by-line analysis to maintain a focused engagement with the data (i.e. to avoid superficial reading) and to generate comments for subsequent analytic processes. Through the commenting process, I developed a greater familiarity with the experiential data. Moreover, I also started to develop some insight into how participants thought about and understood MS-F as a FOL.

In line with Smith et al. (2009/2012c), I made three different types of comments during the commenting processes. The three different types of comments I made were descriptive comments, linguistic comments, and conceptual comments. Descriptive comments focused on describing the overt content in participants' accounts (Smith et al., 2009/2012c). Whilst making descriptive comments, I attempted to remain as close as possible to participants' explicit meanings. As for linguistic comments, these comments focused on exploring the ways in which language is used to convey content and meaning (Smith et al., 2009/2012c). I made linguistic comments by interpreting relevant linguistic features within the transcript (e.g. pauses or laughter). Through linguistic commenting, I came to a deeper and more qualifying understanding of the significance of MS-F within participants' lives. Lastly, conceptual comments were more interpretative in nature and reflected a more interrogative and conceptual engagement with the data (Smith et al., 2009/2012c). I made conceptual comments by interpreting participants' more overarching perceptions of MS-F. In doing this, I made sure that my conceptual interpretations remained closely linked to data segments. Through conceptual commenting, I generated a set of provisional understandings of what

MS-F may signify in life (note that I did not identify the exact understanding itself). As such, conceptual commenting permitted my analysis to transcend a superficial and descriptive analysis of the data.

My commenting process was sequential in nature. I started by analysing a transcript solely for descriptive comments, then followed by linguistic comments, and eventually conceptual comments. Thereafter, I proceeded to fluidly engage with the data and comments until I developed an in-depth and detailed understanding of a participant's idiosyncratic experiences of living with MS-F. Here this engagement represented my enactment of the hermeneutic circle (see subsection 3.2.2) to refine and reflect on my commenting process. All comments and notes I made through the discrete commenting processes were combined onto the same transcript in MS Word and differentiated through stylistic text features (See Appendix K for an example). This differentiation visualised linkages and connections between the distinct types of exploratory comments. Moreover, I also commented on similarities, differences, contradictions, and semantic echoes as I proceeded through exploratory commenting. This was done to facilitate a more holistic analytic dialogue throughout transcripts.

4.4.3.3 Step 3: Developing Emergent Themes. During step 3, I [in line with Smith et al. (2009/2012c)] identified themes from the comments I made during Step 2. This identification entailed shifting my analytic focus from the narrative data to the exploratory comments I made. I identified themes by reducing the volume of detail in exploratory comments; whilst retaining the complexity between different types of comments (i.e. their links and patterns). According to Smith et al. (2009/2012c), this shift leads to a close linkage between identified themes and data extracts if exploratory comments were comprehensively made.

I identified themes by interpreting linked comments of local and discrete narrative extracts. Concurrently, I also considered extract-specific exploratory comments in relation to my overall understanding of participants' accounts. Through this, I eventually produced a succinct and expressive statement of what was salient/important from the comments linked to the data extracts.

That is, I identified a theme which captured and reflected the essence of the various comments linked to a narrative extract. Importantly, whilst the identified themes were grounded within data extracts (i.e. a participant's words and thoughts), they were also conceptually abstracted (through interpretation) to convey how participants perceived MS-F as a FOL.

4.4.3.4 Step 4: Searching for Connections across Emergent Themes. During step 4, the interrelatedness of the identified themes is established (Smith et al., 2009/2012c). This is done to cluster relevant themes together and to identify superordinate themes (Smith et al., 2009/2012c). I identified these patterns by importing all themes and their data segments in a participants' account, into a single Microsoft Word document. Hereafter, I separated themes into different Microsoft Word documents so that:

1. Themes with parallel or similar meanings were clustered in the same document.
2. Themes with oppositional or dissimilar meanings where in the same document.

The sorting procedure itself took place through specific techniques which established the links and the nature of the linkages between themes. Here I employed the following techniques as presented by Smith et al. (2009/2012c):

1. Abstraction: This involved clustering similar themes together to generate a superordinate theme.
2. Subsumption: This entailed designating a theme as a superordinate theme since it linked together a set of related themes.
3. Polarisation: This involved examining the oppositional relationships between themes by focusing on their differences. This was used to foster a more nuanced understanding of the connections between themes and superordinate themes.
4. Contextualisation: This entailed the identification of related themes through similar contextual, temporal, and narrative features to construct a superordinate theme.

Establishing the interrelatedness of themes was an iterative process characterised by the hermeneutic circle. As I determined the interrelatedness of themes, I also evaluated the relevance of themes to my research question. I did this to exclude themes which I, throughout an iterative and cyclical analysis, invariantly identified as irrelevant to the research. That is, I eliminated and discarded all themes unrelated to my research aim as specified through my research objectives. Ultimately, I constructed a table to represent each participant's superordinate themes as comprised out of clusters of related themes. Here I also anchored each theme within data extracts from the participant's account of living with MS-F.

4.4.3.5 Step 5: Moving to the Next Case. Upon completing step 4, I moved on to the next case and restarted the analytic process (i.e. steps 1 – 4) on that participant's account. This step was implemented following the analysis of each individual participant's account of living with MS-F. In line with IPA's ideographic commitment, I attempted to bracket off my understanding of MS-F which developed through the analysis of former participants' accounts. Whilst such bracketing is not wholly possible, Smith et al. (2009/2012c) notes that themes may be identified in a case-specific manner through a rigorous and systematic adherence to IPA's theoretical commitments.

4.4.3.6 Step 6: Looking for Patterns across Cases. After analysing all participants' accounts, IPA requires one to identify and interpret meanings and sense-making patterns across cases (Smith et al., 2009/2012c). I did this by printing out each participant's superordinate theme table. Thereafter, I compared the themes and superordinate themes of participants to identify and interpret patterns in how participants understood MS-F as a FOL. Here I used this cross-case comparison to:

1. Identify themes and superordinate themes which were most salient across cases.
2. Identify and interpret shared themes and superordinate themes which reflected communal understandings of MS-F in the sample.
3. Identify and interpret similar/related themes and superordinate themes to come to an understanding of: (a) how they link with shared meaning and sense-making processes, and (b) to what extent they reflect a participant's idiosyncratic understanding of MS-F.

4. Identify and interpret divergent and contradictory themes and superordinate themes to come to an understanding of: (a) nuance within shared meanings of MS-F, (b) alternative meanings of MS-F, and (c) participants' idiosyncratic understandings of MS-F.

Throughout an iterative cross-case comparison process, I developed and continuously refined thematic structures reflective of how participants understood MS-F as a FOL. Here these thematic structures consisted of themes nestled in superordinate themes and grounded in narrative extracts. Notably, these thematic structures were used in writing up the research findings.

4.5 Reflexivity and Bracketing

As mentioned in Chapter 3, IPA's descriptive phenomenological stance posits reflexivity and bracketing as central to being phenomenological in research (Smith et al., 2009/2012a). As such, I present an overview of my method for being and becoming phenomenological during my analyses. Please note that this section does not seek to provide an in-depth and detailed account of what insights I achieved through reflection and bracketing. Much rather, this section seeks to convey what being phenomenological during IPA analyses entailed in a more general sense. Broadly speaking, I became phenomenological during data analyses through two reflexivity and bracketing approaches. These approaches were: (a) reflexivity and bracketing in anticipation of data analysis, and (b) reflexivity and bracketing during data analysis. I provide a synopsis of these approaches in the following subsections. Nevertheless, it should be noted that it is improbable that I identified all my personal features which could have influenced the research findings. Likewise, it is unlikely that I was continually successful at bracketing off all my personal features during data analysis. For insight into what it was like for me to conduct this IPA research study, please refer to Appendix L.

4.5.1 Reflexivity and Bracketing Prior to Data Analysis

Prior to starting with data analysis, I reflected on my background and positionality to identify personal features which could have distorted the research findings. Through a process of self-reflection, I identified an array of personal features which posed a threat to being phenomenological during data analysis. Broadly speaking, these personal features can be categorised as my: (a) individualist worldview, (b) theoretical preferences and inclinations, (c) socially constructed values and beliefs, (d) tacit understanding of the fatigue that I experience, and (e) my literature-based preconception of how PwMS understand MS-F. Prior to engaging with the data, I actively attempted to bracket off my personal features to minimise artefacts within the data. Here I attempted to temporarily suspend my every day, taken-for-granted sense-making processes and adopt a more phenomenological attitude with respect to the data – something which would permit me to come to a better/closer understanding of how participants understood MS-F as a FOL.

4.5.2 Reflexivity and Bracketing During Data Analysis

As the data analysis process proceeded, I recurrently reflected on the interpretations I made during the data analysis process. This was done in accordance with IPA's interpretative phenomenological stance and the hermeneutic circle as outlined in subsection 3.2.2. Here this recurrent and iterative reflexivity involved me persistently questioning the interpretations I made. For example, I would recurrently ask myself:

1. Do my interpretations adequately reflect what participants sought to convey?
2. Are the interpretations I make data driven?
3. How do my interpretations link with the more holistic account of living with MS-F?
4. To what extent/degree are my interpretations influenced by my prior interpretations?

Through an iterative and extensive interrogation of my interpretations (over and above the examples listed) I was better able to identify those aspects of my typical sense-making processes (i.e. my preconceptions) which needed to be bracketed. Moreover, an interrogative approach to my interpretations also served to refine my interpretations so that they could more accurately reflect participants' sense-making of MS-F. Accordingly, reflection and bracketing during data analysis ensured that I remained devoted to IPA's phenomenological and ideographic commitments.

4.6 Ethical Considerations

4.6.1 Ethical Approval

Ethical approval was requested and obtained from the Health Research Ethics Committee (HREC) of the Faculty of Medicine and Health Sciences at Stellenbosch University (HREC Reference number: S18/07/151) (See Appendix M). The approval process entailed a research proposal being reviewed by the Ethical Screening Committee of Stellenbosch University's Psychology Department followed by the HREC's review (Project ID: 7662). Concurrently, I contacted the director of the MSSA's WC branch who indicated her willingness to assist this research project by facilitating recruitment (See Appendix N).

4.6.2 Informed Consent

Informed consent was obtained prior to data collection through the co-signing of an informed consent form by me and each prospective participant. This form communicated to prospective participants the: (a) research purpose and procedure, (b) responsibilities of participants, (c) potential risks linked to participation, (d) benefits to participation, (e) whether they would be remunerated, and (f) the strategies employed to protect personal information and the collected data. Participants were also informed that their participation was entirely voluntary and of their right to discontinue/retract their participation at any point during or after data collection without suffering any negative consequences. Furthermore, participants were also informed that I would cover all costs linked to the research and that participation would not be remunerated. Nonetheless, I sent each participant a R100 Takealot gift voucher as a token of my appreciation for their contribution to this research study.

Prospective participants were emailed an informed consent form on which the afore-mentioned points were highlighted and relayed in detail (See Appendix O). I also urged them to contact me should they have any concerns, queries, or issues about what the research and/or participation would entail. Here the co-signed informed consent form also served as an information sheet which participants could refer to as needed.

4.6.3 Risk Management

This study posed a medium risk to participants. In anticipation of the possible psychological distress caused by participation, I requested that participants communicate to me: (a) any uncomfortable or distressing feelings/experiences which arose during interviews, and (b) their needs with regards to such experiences. Additionally, I arranged referral routes with the Welgevallen Community Psychology Clinic (WCPC) and MSSA to mitigate risk linked to participation. The WCPC indicated their willingness to address any potential psychological distress resulting from participation through: (a) free face-to-face clinical services if participants could attend sessions in Stellenbosch, and (b) free telephonic psychological support should participants be unable to attend sessions in Stellenbosch (See Appendix P). As for the MSSA, Non Smit communicated their willingness to provide participants with psychological support with regards to their MS diagnoses through: (a) telephonic/email support services, and (b) the MSSA’s Facebook support group (See Appendix Q).

4.6.4 Confidentiality

Whilst it was impossible to ensure complete anonymity, I ensured that the collected data remained confidential through several strategies. Firstly, I anonymised interview data by assigning code identifiers (P1, P2, etc.) to participants to delink them from their narratives when analysing data and reporting findings. Here the assignment of code identifiers was in accordance with the chronological sequence in which the interviews were conducted. Furthermore, I ensured the security of the data by encrypting and storing data on a password protected computer. Data security was further upheld by restricting access to collected data to ensure that only I, my supervisor, and co-supervisor had access to the collected data. Additionally, confidentiality was also upheld when employing a transcriptionist to transcribe the audio-recordings by:

1. Requiring the transcriptionist to sign a confidentiality agreement that they would: (a) uphold the standards of confidentiality, (b) securely store electronic copies of the audio-

recordings and transcripts, and (c) would destroy all the data in their possession upon my request (See Appendix R).

2. Maintaining data security by providing the transcriptionist with restricted access to data. More specifically, they were provided with temporary access to only the interview audio-recordings until they finished transcribing the interviews.

Building on this, confidentiality was also maintained by not relaying the personal information of participants to any agency, party, or individual that was not my supervisor, co-supervisor, or transcriptionist. Concurrently, the contact details of participants were not used for any purpose beyond that of conducting the present research study. As per the policy of Stellenbosch University, the collected data will be retained for a minimum of 5 years.

4.7 Trustworthiness

The analytic veracity of the findings in the current study was assured through rigour in the analytic process and measures aimed at enhancing the trustworthiness of the findings. My conceptualisation of what constitutes a trustworthy study was routed within the seminal work done by Lincoln and Guba (1986) and Guba and Lincoln (1994). Whilst these works are dated, their idea of trustworthiness remains relevant to contemporary social research approaches (Bryman, 2012b). In line with Lincoln and Guba (1986) and Guba and Lincoln (1994), I regarded a “trustworthy study” as one characterised by four qualitative criteria. These criteria were credibility, transferability, dependability, and confirmability. In the following subsections, I discuss how I ensured each of these criteria to enhance the trustworthiness of the findings.

4.7.1 Credibility

Credibility may be thought of as the qualitative equivalent of internal validity in quantitative research (Bless et al., 2014c; Bryman, 2012b). The credibility of the findings refers to the degree to which the data/findings align with and reflect the perceived reality of participants (Guba, 1981). As such, credibility is concerned with how believable, acceptable, and trustable findings are (Hornby, 1998) and whether the findings reflect the reality under investigation (Bless et al., 2014c). The credibility of the findings can be ensured through good research practice (Bryman, 2012b) and methodological strategies such as triangulation (Bryman, 2012b; Lincoln & Guba, 1986) or member checking (Mays & Pope, 2000; Morrow & Smith, 2000).

Credibility was a central concern to my research approach. I enhanced the credibility of findings by embedding credibility facilitating measures within the research methodology. Such credibility facilitating measures included:

1. Purposively sampling participants according to a specific set of criteria. These criteria ensured that recruited participants were well positioned to answer the RQ.
2. Analysing only the most sophisticated and data rich accounts of those living with MS-F. This allowed me to better identify and interpret those more comprehensive understandings of what MS-F signified in life.
3. Developing and implementing a research process cognisant of features which may have confounded MS-F by contributing to MS-F experiences. This involved excluding participants who presented with inessential confounding features (e.g. a recent/current MS-related relapse). Those confounding features which could not feasibly be excluded (e.g. other mental or health conditions) were identified and described in the results.
4. Developing and enacting a research strategy which was philosophically coherent to IPA as a theoretical approach. The philosophical undercurrents of IPA (i.e. phenomenology, hermeneutics, and ideography) were central to methodological considerations beyond mere data analysis. With respect to this, IPA's philosophical pillars informed the adopted research paradigm, the development of the interview guide, my interviewing style, and how I presented the findings.

In addition to the credibility facilitating measures, I also employed certain strategies to heighten the credibility of the findings. These strategies included:

1. Being committed to understanding each participant's idiosyncratic understanding of living with MS-F. To this effect, I: (a) reflected and attempted to bracket off my

personal features and preconceptions of MS-F which could have distorted the findings, and (b) minimised confirmation bias during data analysis by avoiding literature on how PwMS experience, describe, or perceive MS-F.

2. Making use of spot member checking throughout interviews with participants. Spot member checking involves asking clarifying questions during interviews to understand data how participants intended it to be understood (Mays & Pope, 2000). I asked clarifying questions in my interviews when elaboration was needed and to test my own understanding of the data. Here spot member checking provided an immediate means by which to check whether my initial insights matched participants' understandings.
3. Analysing untranslated verbatim transcripts. This circumvented the introduction of artefacts into data sets through translation.
4. Using rich verbatim quotes from numerous participants to ground interpretations and illustrate themes in the results chapter.
5. Continuously reflecting on and refining my interpretations as I engaged in numerous iterations of interpretation.
6. Conducting and analysing follow-up interviews with participants who stated that they were diagnosed with clinical depression. This enhanced credibility by providing insight into whether participants could differentiate MS-F from depression-related fatigue.

4.7.2 Transferability

Transferability may be regarded as a qualitative parallel to external validity in quantitative research (Bless et al., 2014c; Bryman, 2012b). As a criterion of trustworthiness, transferability refers to the degree to which findings from one setting/situation/sample may apply to other similar settings/situations/samples (Bless et al., 2014c; Thomas & Magilvy, 2011). Seeing as the transference of findings constitutes a judgment act by future researchers (Bryman, 2012b), I provide insight into the appropriateness and parameters of potential transference. I did this based on recommendations by Guba (1981) which may render the preliminary transference of findings to other settings/situations/samples more appropriate (Bryman, 2012b) and permissible (Bless et al., 2014c). The recommendations I employed to inform whether a preliminary transference of findings is appropriate include:

1. Recruiting participants through purposive sampling according to specific inclusion/exclusion criteria.
2. Providing a rich description of the sample and participants in terms of demographic and clinical features.

Through a rich description of the sample and sampling criteria the reader can determine whether a setting/situation/group is similar enough to that of participants in this study to permit transference. It should, however, be noted that the intent of the findings is not to be generalised to population groups; rather the value of the findings is routed in the inferences which may be made to theory. Consequently, any transference of the findings to similar settings/situations/samples should be regarded as tentative and preliminary until proven otherwise.

4.7.3 Dependability

Dependability can be thought of as the qualitative equivalent of reliability in quantitative research (Bryman, 2012b; Thomas & Magilvy, 2011). As an equivalent, dependability is akin to, yet different from, reliability (Bless et al., 2014c). Reliability in quantitative research is concerned with the consistency with which a measurement instrument measures whatever it measures (Foxcroft & Roodt, 2018). Whereas quantitative analytic tools are standardised, qualitative analytic tools (i.e. researchers) are dynamic, malleable, and imbedded within the world. As such, it is difficult to maintain analytic consistency throughout qualitative research processes. Unsurprisingly then, dependability is concerned with "trackable variance" in the research process such as changes in research methodology (e.g. adaptions to sampling procedure) or the researcher (e.g. reality shifts) (Guba, 1981). According to Bless et al. (2014c), the dependability of the findings can be ensured through a considered research process and by providing a thorough account of what the research process entailed. With respect to this, Guba (1981) emphasises an in-detail record of data collection and data analysis as being particularly useful to heightening the dependability of qualitative enquiries. Based on these recommendations, I enhanced dependability by:

1. Providing a detailed description of the research methodology employed in this study.
2. Keeping an audit-trail with several documents which kept track of the research process. One document served administrative purposes in that I used it to record my progress during sampling and data collection. Additionally, six documents (one for each participant) recorded how my interpretations developed throughout data analysis. Lastly, I also kept a journal to chronicle my process of identifying and refining themes and superordinate themes

4.7.4 Confirmability

Confirmability may be thought of as the qualitative parallel to objectivity (Bryman, 2012b; Morrow & Smith, 2000). Since complete objectivity is unattainable (Bryman, 2012b), confirmability is concerned with the researcher’s impartiality to the research findings (Guba, 1981; Lincoln & Guba, 1986). Thus, confirmability is concerned with whether findings are data driven or whether the researcher’s positionality had an extraordinary impact on the findings (Bryman, 2012b). As a criterion of trustworthiness, confirmability is attainable by ensuring and establishing the credibility, transferability and dependability of the findings (Thomas & Magilvy, 2011). In accordance with Guba (1981) and Thomas and Magilvy (2011), I enhanced the confirmability of the findings by:

1. Reflecting on, and attempting to bracket off, personal features and preconceptions of MS-F which could have distorted findings.
2. Minimising data distortion emanating from the interview process. I did this by building rapport with participants prior to conducting interviews (i.e. through research-related correspondence and administration of a screening questionnaire). Furthermore, interview attributable data distortions were also minimised through features of my interviewing style. Such features included: (a) an avoidance of leading questions, (b) a commitment to

listening more and speaking less, and (c) using probes so that participants could clarify, expand, and/or contextualise what they spoke about.

3. My supervisors' auditing of the data analysis process. This guidance permitted data analysis to proceed in line with IPA and my research aim. Additionally, my interpretations and research findings were also reviewed by my supervisors. Here my supervisors provided checks and balances to my interpretations and findings.

4.8 Conclusion

This chapter highlighted the present study as an exploratory and cross-sectional research study with a phenomenological approach to inquiry. A screening questionnaire was used to purposively sample participants according to explicit inclusion/exclusion criteria. These inclusion/exclusion criteria ensured that only relevant participants who were well positioned to answering the RQ would be recruited. Recruited participants partook in individual and audio-recorded semi-structured telephonic interviews whereafter they completed a post-interview battery of instruments. The data collected during the interviews were primary to answering the RQ whilst the data collected through questionnaires were largely used for descriptive purposes. Thus, despite this study using some quantitative methods, the present study remains a qualitative endeavour. Participants' accounts of living with MS-F were transcribed and subject to IPA analysis. This involved the use of an iterative, reflexive, and flexible data analysis procedure imbedded within an overarching data analysis strategy. Here IPA analysis served as the method by which I could interpret how participants understood MS-F as a FOL. As discussed, this research study sought to improve data quality, enhance trustworthiness, and remain congruent with IPA's theoretical foundations. All these commitments suggest that the present research study was well positioned to generate high-quality research findings.

Chapter 5: Results

In this chapter, I present the results of my exploration into how PwMS in the WC understood MS-F as a FOL. I start this chapter by describing the demographic and clinical features of the participants who partook in this study. Subsequently, I report the findings of the IPA analysis through four subsections, respectively dedicated to my research objectives. Here I first report on how participants made sense of MS-F as a symptomatic experience. Thereafter, I present my findings on how participants understood MS-F's impacts on their everyday life. Following this, I detail how participants made sense of MS-F management, before reporting on how participants understood coping with MS-F. Through these four subsections I aimed to provide an in-depth and nuanced account of how I understood participants' lived experiences of MS-F. Finally, I conclude this chapter with a brief synopsis of what was presented in this chapter.

5.1 Sample Characteristics: Demographic and Clinical Features

In total, I was contacted by 30 prospective participants of which 12 met my inclusion criteria and participated in interviews. I reached data saturation at my 10th interview but conducted two more interviews to confirm that data saturation had been reached. During the last two interviews, questions and probes did not elicit any novel descriptive content. Accordingly, I resolved that data saturation had been reached. Subsequently, I assessed the sophistication of the 12 audio-recorded interviews. Based on Fusch and Lawrence's (2015) recommendations, I listened to, and carefully considered, each narrative in terms of its data richness and thickness (see subsection 4.2.2). Through this subjective evaluation process, I selected the six most sophisticated narratives into the final sample. I excluded six narratives as follows:

1. Three experiential narratives where not sophisticated enough for me to conduct an in-depth and rigorous IPA analysis. These accounts where not adequately rich and thick in meaningful reflections of what living with MS-F implied and signified. As such, I excluded these accounts from the final sample.

2. Three experiential narratives where relatively less sophisticated when compared to the remaining six experiential accounts. Whilst these accounts where sophisticated enough for IPA analyses; they were less rich and thick in meaningful reflections. As such, I deselected these narratives from the final sample.

For a detailed account of how the present study's sampling procedure was enacted please see Appendix S. The final sample's demographic composition is provided in Table 5.1 below, whilst the sample's clinical features are presented in Table 5.2 (see next page).

Table 5.1

Demographic Composition of the Sample

	Demographic Features			
Participants	Age in Years	Gender	Racial Identity	First Language
P1	30	Female	White	English
P2	62	Female	White	English
P3	35	Female	White	Afrikaans
P4	44	Female	White	English
P5	41	Male	White	Afrikaans
P6	64	Male	White	Afrikaans

As illustrated in Table 5.1, the sample consisted of self-identified white individuals of which the majority were female (n = 4) and middle-aged adults (n = 4). Whilst all participants were proficient in English, English was the first language of half the sample with the rest being native Afrikaans speakers. Furthermore, most participants (n = 5) were of a middle-income socio-economic status with one participant being from a high-income bracket. All participants in the sample have graduated from a tertiary institution and had full-time employment at the time of the research.

Table 5.2

Clinical Features of the Sample

	Clinical Features					
Participants	Age when diagnosed with MS	Age at MS Symptom Onset	MS Subtype	Subjective FI	CFQ assessed FI	Disability Status
P1	25	24	RRMS	Moderate	Insignificant FI (CFQ = 4)	Mild
P2	48	12	SPMS	Moderate	Significant FI (CFQ = 9)	Severe
P3	30	16	RRMS	Severe	Significant FI (CFQ = 5)	Moderate
P4	30	30	RRMS	Severe	Significant FI (CFQ = 8)	Moderate
P5	18	18	RRMS	Moderate	Insignificant FI (CFQ = 4)	Mild
P6	56	16	PRMS	Moderate	Significant FI (CFQ = 8)	Severe

Note. FI = Fatigue Intensity; CFQ = Chalder Fatigue Scale; RRMS = Relapsing-remitting multiple sclerosis; SPMS = Secondary progressive multiple sclerosis; PRMS = Progressive relapsing multiple sclerosis.

As demonstrated in Table 5.2, most participants were diagnosed with MS during early adulthood ($n = 4$), with their first MS-related symptom presenting during either adolescence or early adulthood ($n = 5$). All participants reported their symptomatic experience of MS-F to be either moderate ($n = 4$) or severe ($n = 2$) in intensity. Nonetheless, two participants could be classified by their CFQ scores as not presenting with problematic fatigue. Whilst no participants suffered from any neurological condition other than MS, most participants stated that they were diagnosed with clinical depression ($n = 4$). Furthermore, three participants suffered from other major health conditions which could have contributed to MS-F’s severity and/or influenced their experience of

MS-F. With respect to this, P2 suffered from hypertension, P5 from sleep apnea and high cholesterol, whilst P6 suffered from Raynaud's disease.

5.2 Participants' Sense-making of MS-F as a Symptomatic Experience

When speaking about MS-F's symptomatic experience, participants described MS-F in terms of its symptomatic characteristics, their intrapersonal experiences, and their past experiences. The content of participants' accounts, at a more descriptive level, included broad swathes of topics such as (for example) MS-F's temporal patterns, onset, severity, aggravators, and what MS-F felt like. As such, more descriptive quotes are commonly cited within this section. Nonetheless, it is essential to note that this section does not seek to provide a comprehensive description of MS-F as a symptom. Much rather, this section reports on those over-arching meanings and shared perceptions underlying the various topics in participants' accounts.

Through my analysis, I identified a single superordinate theme as reflective of how participants made sense of MS-F's symptomatic experience. This superordinate theme was a sense-making process in which MS-F was understood through its symptomatic features. Here this higher-order sense-making process comprised three highly recurrent themes. These themes were perceptions of MS-F as: (a) a lack of energy, (b) an ever-present inconsistency of life, and (c) a subjective mind-body phenomenon. The higher-order sense-making process, and subsumed perceptions of how participants made sense of MS-F as a symptomatic experience, are visually presented in Figure 5.1 on the next page.

Figure 5.1

Participants' Sense-making of MS-F as a Symptomatic Experience

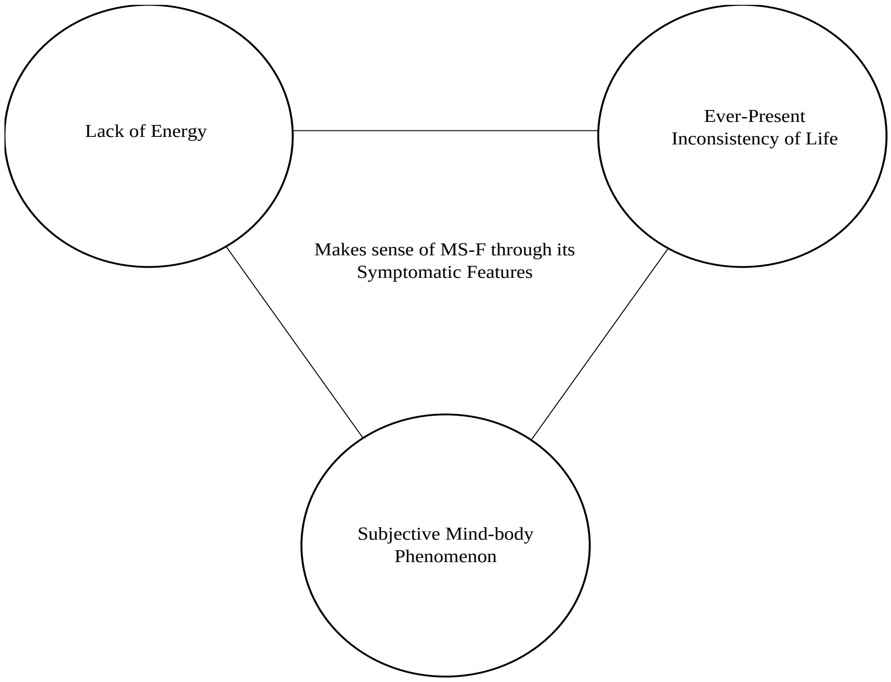

Figure 5.1. Visual illustration of the perceptions/themes (see writing in circles) implicated in an understanding of MS-F through its symptomatic features (see writing in triangle). Lines between themes symbolise linkages.

Figure 5.1 provides a holistic yet reductionist overview of my findings on how participants understood MS-F as a symptomatic experience. In this figure, the distinct perceptions are most important since they represented the ways in which participants understood MS-F as a symptom. As such, I present these three different perceptions in the following subsections. For a quick overview of these perceptions and their comprising notions see Table T1 in Appendix T.

5.2.1 MS-F as a Lack of Energy

All participants perceived a lack of energy as a central feature of MS-F's symptomatic experiences. This was evident in that participants regarded a lack of energy as nearly synonymous with MS-F and a salient characteristic of MS-F. The former semantic pattern is illustrated by P5 who equated MS-F's symptomatic experience to a state of near absolute energy depletion: "It's just like it's, almost like your car battery that's, that's gone flat. There's no reserves, that's the best way I can explain it." This quote highlights the fatigued self as devoid of the energy needed to continue functioning. Contextualising this, P5 also demonstrated the latter semantic pattern by designating a lack of energy as a primary characteristic of MS-F experiences ("…with MS, the fatigue element of that is, lack of energy."). Akin to P5, all other participants perceived a state of energy depletion as salient in MS-F's symptomatic experience. For instance, P2 regarded her present self as energy deprived ("I don't have the energy. I-I'm just totally tired.") whilst P4 defined MS-F as a state of bodily resource depletion ("…the body runs out of resources and that is definitely MS-related fatigue."). Whilst a lack of energy was typically described as a state of physical resource depletion; it was also described as a mental phenomenon. Take, for example, P1 who recounted her experience of mental resource depletion when fatigued: "…you can actually feel it in your brain, so to say. It's like it feels fatigued, it feels used up, wrung out like a sponge." Accordingly, it seems that the lack of energy in MS-F may enshrine both a physical and a mental state of resource depletion.

A salient feature characterising participants' accounts was that ambiguous lay terms were often used to refer to MS-F. This included words such as "tiredness", "fatigue" and "exhaustion". Nonetheless, participants emphasised MS-F to be distinct from lethargy and the fatigue experienced by healthy individuals. MS-F was perceived as different from tiredness, sleepiness, and lethargy in that MS-F was characterised by a pronounced energetic depletion. Here participants regarded a lack of energy as the central feature that distinguished MS-F from the fatigue experienced by others. This distinction is exhibited by P5 when comparing MS-F to tiredness:

> … tiredness is not exactly it, tiredness is "I wanna go to sleep 'cause I'm tired." … There's tiredness involved but there's also uh, lack of, say, I can say, lack of energy to, … to work, to do whatever you're supposed to do, whatever you want to do. So, fatigue is a combination of "I'm tired" but, also "I don't have energy".

The lack of energy in MS-F was regarded as being a very pronounced and undesirable phenomenon. Consider, for instance, P3's description of his fatigued self: "I feel like shit, heh heh heh (Exhales). That's what it feels like." Through this quote, P3 conveys that a lack of energy is a horrible subjective experience. Moreover, P3's characteristic laughter, exhalation, and use of the word “shit” indicates that the energetic depletion in MS-F is very pronounced. For some, this lack of energy could be so severe that it signified an intolerance for further energy expenditure. Take for example P2 who described her lack of energy as so severe that relatively effortless tasks became too energy-intensive to perform: “You’re so tired that you don’t even have the energy to pick up your head. That’s how tired you can get at times.” All in all, the severity of MS-F was incomparable with any other type of fatigue participants experienced (e.g. typical tiredness and sleepiness). Consider, for instance, P6 who designates a lack of energy as more severe in MS-F than in bodily over-exertion: “Um, maybe like a late night out drinking a helluva lot and then only have a few hours’ sleep and getting up (pronounced exhalation) (pronounced inhalation), I don’t even think that will match it.” This quote illustrates the degree to which energy is, or may be, lacking when experiencing MS-F. An important notion, given that most participants thought that others not suffering from chronic fatigue did not, and could not, grasp the severity of MS-F.

Notably, participants did not perceive the severity of a lack of energy (i.e. the severity of MS-F itself) as rooted solely within their MS diagnoses/progression. Much rather, participants described personal features (e.g. age) and differences in everyday life (e.g. stress and workload) as co-contributors to MS-F’s severity. As such, the severity of MS-F appears to have a multicausal basis which may change over time (e.g. through aging) and across settings (e.g. changes in workload). Moreover, it should be noted that fatigue was described as a symptom of depression by several participants who were diagnosed with depression. Most of these participants designated a lack of energy as a characteristic of both MS-F and fatigue in depression. Nonetheless, participants could distinguish MS-F from fatigue in depression (albeit with some difficulty). Here participants emphasised fatigue in depression as distinct from MS-F by being a more “fatalistic” type of fatigue. This more fatalistic fatigue was articulated as a “tiredness to the bone” that was typified by a loss of motivation and accompanied by pronounced despair. These characteristics were not identified with respect to participants’ symptomatic experience of MS-F.

5.2.2 MS-F as an Ever-present Inconsistency of Life

This theme consists of two related subthemes. These subthemes were perceptions of: (a) MS-F as an ever-present FOL, and (b) MS-F as an inconsistency in life. Note that these perceptions were related in that they pertained to MS-F's temporal characteristics.

5.2.2.1 MS-F as an Ever-present Feature of Life. Participants perceived MS-F as an ever-present FOL which persists across life. This is clearly the notion which P3 attempted to convey when describing MS-F as follows:

> It's a constant companion; it's not something that goes away. I mean, you can have good and bad days and some days I don't have paraesthesia and some days I don't have vertigo, and some days I don't even have pain but I have fatigue every, every day.

Through this quote P3 emphasises MS-F as an everyday phenomenon and an assured future occurrence (i.e. something that is persistent across life) which changes in severity. A perception of MS-F as an ever-present FOL was also evident in other participants' accounts. For example, P2 described MS-F as "a chronic tiredness" whilst P4 specified MS-F as an everyday FOL ("I'm literally tired every day."). Moreover, participants also revealed a perception of MS-F as an ever-present FOL by regarding MS-F as a never-ending FOL. This notion of MS-F being a never-ending FOL was evidenced by participants highlighting MS-F as an unavoidable and inevitable symptom. Take for example P5 who described MS-F as "an unwelcome guest that you can't get rid of" and an assured component of the future ("…this is not going to stop; this is going to go on."). Nevertheless, it was P3 who most comprehensively relayed MS-F's never-ending nature:

> Um, it's just the severity that – that, changes from day to day. So it's just, it's a constant thing. It's something you carry with you everywhere you go, all the time. You can never get rid of it there (pronounced exhalation), there's no medication, there's no nothing that works for it.

This quote is particularly insightful since it captures how MS-F, through its persistence and inescapability, is a substantial burden in the lives of MS-F sufferers. Moreover, this quote highlights how a life without MS-F is unattainable despite engaging in fatigue alleviation/dissipation strategies. Something which reveals MS-F's obstinance and resistance to alleviation/dissipation. Take for example the following quote by P1, which describes how MS-F may persist despite sleep:

> Um, before the MS symptoms, it was um, you know if you had like a late night or you stayed up studying all day, all weekend and then you'd feel tired. You'd feel like, "Oh okay. I'm gonna have a nap, I'll be fine." Or "I'll go to bed at like 9, I'll be fine. I'll be up and going the next day." Um, whereas with MS, you-you can nap and you might wake up just as tired, or you might go to bed early and still wake up exhausted…

This extract highlights that, for P1, MS-F is a symptom that has the potential to persist despite sleep. Similarly, other participants regarded MS-F as obstinate and frequently resistant to MS-F alleviation/mitigation strategies (see section 5.4.2). Here this obstinance and resistance to alleviation/mitigation further illustrated that participants perceived MS-F as an ever-present FOL.

5.2.2.2 MS-F as an Inconsistency in Life. In addition to perceiving MS-F as an ever-present FOL, most participants also perceived MS-F as an inconsistency in life (i.e. an inconsistent phenomenon within everyday life). This perception was evidenced through two notions shared by several participants. These notions where that MS-F is an episodic phenomenon, and that MS-F is characterised by a variable severity.

Most participants relayed a notion of MS's episodic nature by speaking about MS-F as if it was a momentary or transient state. Take for example P1, who described MS-F as manifesting through temporally discrete experiences ("Um, ja, when I'm experiencing it. Obviously, it's not all the time…") or P4 who regarded MS-F experiences as states to be endured ("I have to say to myself, 'P4, it is not your fault, remember who you are in just this moment.'"). Furthermore, participants conveyed a notion of variable MS-F severity by describing how changes in energy implied changes in MS-F's severity. Here MS-F's severity appeared to be intimately interwoven with changes in energy reserves such that: (a) greater energy reserves implied no/milder MS-F experiences, (b) whilst lesser energy reserves implied more severe MS-F experiences. This connection was well illustrated through P1's use of a metaphor which linked changes in energy reserves to changes in MS-F's severity:

> There's a cliché, um, analogy when they say with MS you wake up with a bucket full of water and throughout the day, you scoop out water out the bucket. And you only have so much water to scoop out and some days you only wake up with half a bucketful, and other days you wake up with nothing in your bucket.

Taken together, MS-F's episodic nature, transience, persistence, and variable severity suggests that MS-F is experienced as a series of transitory states interspersed with periods of no/less fatigue. Moreover, different MS-F episodes seem liable to vary in their severity. Accordingly, it appeared that participants perceived MS-F as an inconsistency in life. Here this finding was consistent and congruent with all participants' accounts of living with MS-F.

Notably, MS-F appeared to follow idiosyncratic patterns within participants' everyday lives. For example, P5 described severe MS-F as occurring in the mornings and largely absent in the afternoon: "I do suffer a bit, especially in the morning with fatigue. I'm-I'm for some or other reason I'm-I'm, I'm better in the afternoons, I'm more awake during the afternoons…." Whilst participants regarded MS-F's patterns of onset/aggravation as anticipatable in daily life; not all MS-F episodes were appraised as being predictable/foreseeable. Much rather, some participants regarded MS-F onset/aggravation to be random and spontaneous on occasion. Thus, it appeared that MS-F constituted a partially anticipatable, yet partially unforeseeable, phenomenon. This finding is consistent with the finding that most participants perceived MS-F as an inconsistency in life.

5.2.3 MS-F as a Subjective Mind-body Phenomenon

Participants perceived MS-F as a symptom which manifests through subjective intrapersonal phenomena. Several participants regarded MS-F to be a symptom that manifests through both physical and mental phenomena. This was most clearly illustrated by P3 who regarded MS-F as a mind-body phenomenon ("…it's not just mental, it's a physical thing as well."). Similar notions were also espoused by other participants. For instance, P4 highlights MS-F as both physical ("…so for me it's physical…") and mental in nature ("I would say that you are more almost like mentally tired."). Nonetheless, whilst all participants perceived MS-F as being mental in nature (i.e. as expressing through mental phenomena); a perception of MS-F as being physical in nature (i.e. as expressing through physical phenomena) was not ubiquitously shared by participants. This latter notion may be gleaned from P1's description of MS-F as mental exhaustion and a non-physical phenomenon: "I'm very active at work, um, it's not, doesn't physically tire me out, it-it's just mental exhaustion." Through this quote, it appeared that P1 regarded MS-F to manifest as a fatigued mind within a non-fatigued body. Similar notions were also conveyed by both P5 and P6. Considered as a whole, manifested MS-F seemed to constitute a mind-body phenomenon characterised by some degree of idiosyncratic variation. This is evident in that whilst MS-F was predominantly perceived as mental in nature; MS-F was also perceived as physical in nature by several participants. In the following subsections, I report on MS-F as a subjective mind-body phenomenon in more detail through its constituent subthemes/notions.

5.2.3.1 MS-F as Mental in Nature. As reported previously, all participants perceived MS-F as mental in nature. This perception was evidenced in that participants regarded MS-F as implicating the mind and manifesting through mental phenomena. MS-F's mental manifestation appeared to involve mental alterations which accompanied MS-F and impaired mental functioning. Consider for instance the following statement by P2: "…my brain's not functioning on its optimal level anymore because I'm tired". This quote illustrates that P2 considered suboptimal mental functioning to be a mental alteration emanating from MS-F. Furthermore, P2 also qualified MS-F's mental alterations as changes which subvert optimal mental functioning, and hence, impair mental functioning. This notion of MS-F inducing mental impairments was recurrent in that it was shared by all participants. Consider for instance P1 who designated mental exertion as untenable when fatigued ("…your brain goes like, 'I'm too exhausted to do this.'") or P4 who highlighted that MS-F results in mental shutdowns ("…it's also as if your-your-your brain kind of shuts off as well."). At a more descriptive level, the present study identified that MS-F manifested through various distressing mental impairments (see Table U1 in Appendix U). Most participants regarded the presence of these mental impairments to be predicated on the presence of MS-F (i.e. a part of the fatigued self). Something which indicated that MS-F's mental alterations where transient and reversible since MS-F itself constituted an episodic phenomenon (see subsection 5.2.2.2).

5.2.3.2 MS-F as Physical in Nature. Several participants perceived MS-F as partially physical in nature. These participants perceived MS-F's physical presentation as comprising two physical phenomena. These phenomena were a functional incapacitation and an altered subjective experience of the physical self.

Some participants regarded MS-F's physical presentation as involving a functional incapacitation of the body. As illustrative of this notion, consider the following statements from P4's account alongside each other:

1. "My body in a way just like says, 'Enough.' It gives up…"
2. "…there's like a shutdown of the body…"
3. "…so for me it's physical, I literally can hit a wall."

These quotes emphasise how, for P4, MS-F altered the physical self in such a way that physical functioning became untenable. Additionally, P4's use of absolutist language (i.e. "I literally can hit a wall", "shutdown", and "'Enough.' It gives up.") qualified this functional incapacitation as being a near complete and insurmountable phenomenon. Akin to P4, P3 also conveyed the notion that MS-F manifests through a functionally incapacitated body. This notion was illustrated by P3 in how she described her experience of MS-F:

> Well, if I had to describe it, it would be… sitting there and realising that if the house started burning, you actually would burn to death because you're too tired to get up, that's fatigue. Whereas if you're tired, you'll still get up, if you're fatigued you just, you physically cannot do it.

This quote by P3 was exceptionally insightful. It illustrated that a functional incapacitation of the physical self is prominent in MS-F's physical manifestation. Moreover, this quote also attested to the sheer and utter helplessness which accompanies her physical powerlessness when fatigued.

Those participants who perceived MS-F as physical in nature also perceived MS-F as altering their subjective experience of their physical selves. This perception was articulated by P3 through the following metaphor:

> Sometimes it feels like you don't belong in your body, like um, you know you – like you don't fit inside, like your body's a little bit too small or-or maybe rather actually too big you know. You have this huge thing to carry along, like someone else gave you their outer shell, and you're inside and you have to carry this whole heavy thing along.

Through this metaphor P3 provided insight into what living in a fatigued body signified for the self. This insight appeared to be that the self is caught within a fatigued body, and that the fatigued body is burdensome and unfamiliar to the self. Like P3, other participants also considered MS-F to manifest through an altered subjective experience of the physical self (albeit in a less abstract manner). Such participants conveyed this notion by speaking about the physical sensations that emanate from MS-F. The physical sensations that participants described as comprised in an altered experience of the physical self is presented in Table V1 in Appendix V. Notably, these sensations appeared to be MS-F induced alterations since: (a) these sensations were atypical occurrences when participants were not fatigued, and (b) participants attributed their experience of physical sensations to MS-F itself.

5.3 Participants' Sense-making of MS-F's Impacts on Everyday Life

Participants described MS-F as impacting various functional domains in their everyday lives. Broadly speaking, these domains included participants' personal, social, familial, occupational, and communal lives. I identified a single superordinate theme as reflective of how participants made sense of MS-F's impacts across the aforenoted domains. This superordinate theme was an understanding that MS-F restricts one's capacity to participate in the world. Here this higher order sense-making process was found to encompass three highly recurrent themes. These themes were perceptions of: (a) a restricted functional capacity, (b) a loss of spontaneity, and (c) a loss of independence. Participants' overarching understanding and perceptions of how MS-F impacted their everyday lives are visualised in Figure 5.2 below.

Figure 5.2

Participants' Sense-making of MS-F's Impacts on Everyday Life

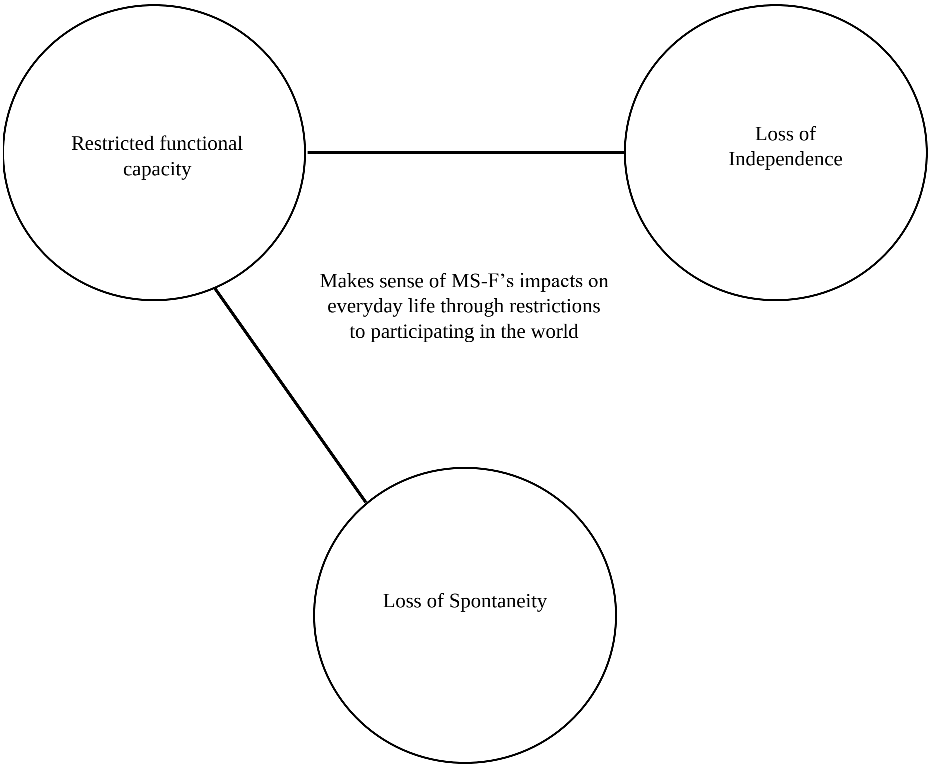

Figure 5.2 Visual illustration of the composite perceptions/themes (see writing in circles) implicated in an understanding of MS-F as restricting one's capacity for participating in the world. Lines between themes indicate linked perceptions.

Figure 5.2 provides a holistic overview of my findings on how participants understood MS-F's impacts on everyday life. Here the perceptions/themes are most important since they constitute functional delimitations through which MS-F restricted participation in the world. I provide an overview of these themes in Table W1 in Appendix W and present them in detail through the following subsections. Note that whilst I provide descriptive insights into MS-F's impacts on everyday life; this section is dedicated to reporting on participants' understandings and perceptions.

5.3.1 Restricted Functional Capacity

A perception of MS-F as restricting participants' functional capacity (i.e. their capability to perform tasks) was espoused by all participants. This perception comprised three related subthemes. Here these subthemes were perceptions of: (a) an MS-F induced functional inhibition, (b) an unfeasibility for extensive functioning in everyday life, and (c) unassured future functioning.

5.3.1.1 MS-F Induced Functional Inhibition. All participants perceived MS-F as inhibiting functioning in everyday life. This perception was most vividly conveyed through accounts of MS-F inducing a functional incapacitation. Take as illustrative of this notion the following quote by P5: "Well, it um, it-it-it prohibits you from doing what you want to do and achieving what you want to do and achieving what you want to achieve." This quote illustrates that P5 considered a loss of functional capacity to emanate from MS-F. Moreover, this functional incapacitation appears to be so pronounced that P5's wish fulfilment and goal attainment was subverted/sabotaged. Other participants' understanding of MS-F's impacts on everyday life also converged with this notion of an MS-F induced functional incapacitation. This convergence was evident through participants' copious descriptions of how task-performance is unfeasible or largely unrealistic when fatigued (e.g. P1's statement that she was "too tired to really do anything" or P6 who reported that he was "too tired to really do things."). Whilst a MS-F induced functional inhibition was most explicitly articulated through accounts of a functional incapacitation; this perception was most frequently expressed as an inability to continue functioning when fatigued. Take for example the following extract in which P2 described her intolerance to prolonged functioning:

> Most people, most people wouldn't have such low um, tolerance. They-they would carry on and go on and go on. I have to rest, I have to take time out and just sit and do nothing and let my brain unwind and just, um, relax.

From this quote, it is evident that P2 regarded herself as incapable of sustaining prolonged functioning. Moreover, P2's incapacity to "carry on and go on and go on" was highlighted as differentiating the lived reality of MS-F sufferers from those not suffering from chronic fatigue. This notion of the fatigued self being unable to sustain prolonged functioning was ubiquitous within the sample. For example, P6 regarded sustained functioning as unfeasible when fatigued ("So, you start with something, then you have to take a break and rest, and then you carry on a bit and then you have to take a break again…"), whilst P5 linked the dissipation of MS-F to the restoration of his functional capacity ("…later the fatigue just half go-goes away and I can get on with, get on with whatever I'm doing.").

The loss of functional capacity when fatigued appeared to arise from a lack of energy (i.e. MS-F's characteristic feature). This finding is well demonstrated by P1 who emphasised that continued functioning was untenable when she experienced severe MS-F:

> Fatigue is like um, you're just so drained, you're exhausted it's just like there's nothing left to continue on with. 'Cause i-it's like you have nothing more to give, you can't think any further, you can't do anything more.

From the extract it appears that P1 regarded a severe lack of energy to be inhibitory since it subverts and prevents continued functioning. This notion that a lack of energy is causal to MS-F's functional incapacitation was shared by all participants. For instance, P5 regarded his subverted wish fulfilment as attributable to a lack of energy ("I want to go out and do something, but I just don't have the reserves or the energy to do it.") whilst P6 linked her inability to perform relatively undemanding tasks to a state of energy depletion ("I don't feel like taking calls. I don't have the energy to take calls.").

Most participants regarded a lack of energy in MS-F as inhibiting both physical and mental functioning (see P1's previous quote for an example). Here MS-F's inhibitory effect on functioning persisted irrespective of whether the task-to-be-performed was perceived as demanding or relatively undemanding from my analytical perspective (e.g. standing for 10 minutes). Moreover, MS-F was highlighted as inhibiting functioning across virtually all domains of life. With respect to this, participants described MS-F as having the capacity to inhibit and subvert functioning in their private lives (e.g. wish fulfilment), domestic lives (e.g. everyday household tasks), romantic lives (e.g. providing emotional support), family lives (e.g. participating in familial activities), and their social lives (e.g. visiting friends). Nonetheless, the specific functional impairments reported by participants were idiosyncratic and varied between participants. Additionally, the degree to which MS-F inhibited participants' functioning also appeared to vary – ranging from a minor functional difficulty to a complete loss of wakefulness. Here the inhibitory power of MS-F seemed to change alongside alterations in MS-F's severity such that more severe MS-F episodes (i.e. greater energetic deficiencies) imposed greater restrictions on functioning.

5.3.1.2 Unfeasibility for Extensive Functioning in Everyday Life. Most participants perceived their restricted energy reserves as preventing extensive functioning (i.e. diffuse task-performance) in their everyday lives. This perception is most vividly evidenced through the following extract from P5's account:

> …there's a lot of things happening in life, and you want to partake, and you want to do things, you want to visit places, visit people, visit, do things, ja live. But... and ja, enjoy your hobbies and so on, but at the end of the day you just don't, most of the things you just don't get to because you just, like I said, you don't have the energy to invest in it. So, it's ja, it's-it-it's-it feels like, ja. In a way as if life is going on and you're not going along with it."

Through this quote P5 conveyed that his available energy reserves are so limited that extensive functioning becomes unattainable and unfeasible in everyday life. Moreover, for P5 this unfeasibility to diffusely participate in the world signified being left behind in life. Something which implied that P5 lives a less fulfilled and contented life because of MS-F. Importantly, P5 did not perceive extensive functioning as unfeasible over a lack of energy for functioning. Much rather, P5 perceived extensive functioning as delimited by his restricted energy reserves. This distinction is evident in that P5 regarded himself as lacking enough energy to "invest" towards diffuse functioning. A term which denoted the presence of energy in some amount as opposed to being devoid of energy. Convergent with P5, P1 also considered her everyday functioning as delimited by her available energy reserves. This notion may be gleaned from the following metaphor in P1's account:

> There's a cliché, um, analogy when they say with MS you wake up with a bucket full of water and throughout the day, you scoop out water out the bucket. And you only have so much water to scoop out and some days you only wake up with half a bucketful, and other days you wake up with nothing in your bucket. And so, so you can't even judge how far you can push yourself until you get that-that fatigue point where you can't anymore.

This metaphor illustrates that P1 considered energy to be a resource which exists in some amount and is expended through daily functioning. For P1, MS-F's functional delimitations in life varied across days according to changes in her energy reserves between days. Moreover, P1 regarded extensive functioning (i.e. an energetic overexertion) as a risk since it could culminate in a loss of functional capacity (i.e., an MS-F induced functional inhibition). Akin to P1 and P5, P3 emphasised an incapacity for diffuse task-performance as a change which accompanies MS-F and distinguishes her past and present selves. Likewise, P2 highlighted how the successful completion of a multitude of tasks in everyday life became untenable because of MS-F. Here P2 described her past self as living an "active lifestyle" and her present self as confined to a "sedatory lifestyle".

Participants' restricted capacity to participate in the world seemed to manifest in how participants approached task-performance in daily life. Because of their functional delimitations, participants typically performed tasks they appraised as essential (e.g. job-related tasks) and avoided the performance of tasks appraised as inessential (e.g. household tasks or recreational activities). This approach to task-performance is illustrated by P3 who described wish fulfilment as an occasional occurrence and need fulfilment as a typical occurrence: "I usually end up doing all the things I have to instead of the things I want to." Nevertheless, participants did on occasion get around to performing inessential yet desirable tasks. Take as illustrative of this point the following quote from P6's account: "It's a bit more effort to do something nice occasionally but yes, I do get around to it at times."

Whilst extensive functioning was prevented by MS-F, this restriction persisted despite the presence/absence of MS-F and functional inhibition. Notably, an unfeasibility for extensive functioning in life seemed to elicit various negatively valanced emotions (e.g. anger and guilt). Additionally, this unfeasibility appeared to contribute to an overall discontent with life and a sense of an unfulfilled life. Furthermore, whilst MS-F restricted diffuse task-performance this delimitation was partially attributable to (i.e. partially emanated from) energy maintenance (see section 5.4.2). This point is particularly relevant to energy conservation since functional restriction was a tactic participants used to manage MS-F.

5.3.1.3 Unassured Future Functioning. Most participants perceived their future functioning as unassured since there was always a possibility for them to experience MS-F in the future. This perception was conveyed by P6 who highlighted that the feasibility of his future functioning was predicated on the presence/absence of MS-F in the future:

> You don’t plan anything, before, long before, you sort of; if I feel alright today then I’ll do something. I don’t… I won’t plan today to go on a breakfast drive with my bike on Sunday. I’ll get up on Sunday and see how I feel and then decide if I’m gonna do it or not. ’Cause if I’m too tired I’m not gonna do it. It’s – you sort of take life day by day and see how you feel.

Through this quote P6 conveyed how MS-F suspends his future in an almost limbo like state. Within this state P6’s future functioning was unassured since his future energy reserves were unknown to him in the here and now. Here it appeared that MS-F, through its partially unforeseeable nature (see section 5.2.2.2), rendered future engagements in the world as tentative/provisional at best. Similar perceptions were also shared by P3 and P4. Consider for instance the following quote in which P3 speaks about the unforeseeable and undependable nature of future functioning:

> …some of his friends went to a quiz night the other night that they wanted me to join. Then I said, “well, I can actually only tell you on Thursday, whether I’ll be able to make it or not.”

> Like, it's – this was the week before and I said, "There's no way for me to know whether I'll be able to make it"… So, that's the way we organise it. I would come at short notice if I could, and I would not show if I couldn't."

What should be noted in P3's quote is that she regarded her ability to function in the future as undependable since this ability was unknown to the present self. Here it was only upon the dissipation of this "unknown" through an arrival of the future that P3 became aware of whether she could continue functioning. In this sense, it appeared that unassured future endeavours became appraised as feasible/unfeasible only by the insight brought through an arrival of the future.

Interestingly, participants highlighted two scenarios in which their capacity for future functioning was known to their present selves. Some participants regarded over-exertion to dependably subvert and sabotage future functioning. Additionally, P2 considered MS-F management as dependable enough that future functioning could be reasonably assured. Nonetheless, P2's notion was ideographic and was not shared by other participants in this study.

5.3.2 Loss of independence

Nearly all participants perceived MS-F as leading to a loss of independence within their everyday lives (particularly within their private and domestic lives). Participants conveyed this perception by highlighting everyday life with MS-F as typified by a loss of self-sufficiency and a greater dependence on others. As illustrative of participants' perceived loss of independence consider the following quote by P2:

> Um, my husband does a lot of tasks at home for me. Like he'll do the cooking, which often he does, and over the weekends, he'll do all the washing for us. Um, so a lot of the things that I could do in the past I can't do anymore because I just don't have the energy.

There are two important points to observe within this quote. Firstly, P2 regarded her present self (i.e. the energy deficient self) as less self-sufficient in daily life than her past self (i.e. a non-energy deficient self) because of MS-F. Thus, it appeared that a loss of independence signified a change which accompanied and arose from MS-F. Convergent with P2's understanding, P1 considered her past and non-fatigued self as “a very independent person” whilst P6 designated independence as a feature of a past life (“…but 10 years ago, I could still do things for myself.”). Secondly, P2 considered herself as reliant on her significant other to complete routine and mundane tasks of everyday life. This reliance on her partner to fulfil rather undemanding tasks in everyday life illustrates that P2’s loss of independence was pronounced and substantial. Consistent with P2, other participants also considered themselves as more dependent and reliant on others when fatigued. For instance, P3 regarded assistance as necessary for her to enact the rather undemanding task of playing: “The cat wants to play fetch, which is great, but if she doesn’t bring back the ball then I can’t get up and fetch it. So, if she doesn’t fetch it then we’re not playing anymore.” Alternatively, consider the following extract from P6’s account which designates a reliance on others as essential to his completion of demanding tasks: “I can’t do any maintenance except check the oil and the water, something like that, something very silly. If it needs work to be done, I must get somebody to do it. There’s no self-help anymore.”

The loss of independence in MS-F appeared to be intimately linked to an MS-F induced functional inhibition (see subsection 5.3.1.1). This was evident in that descriptions of inhibited functioning (e.g. lacking energy for household tasks, familial role fulfilment, and/or social engagements) were often enmeshed with accounts of a loss of independence. Furthermore, a loss of independence was described as a temporal phenomenon that accompanied MS-F’s symptomatic experience. In this respect, a loss of independence seemed to be a reversible phenomenon that dissipated along with the dissipation of MS-F episodes. Notably, whilst a loss of independence was reported in relation to demanding and relatively undemanding tasks; this was not the case for tasks perceived as essential to complete despite MS-F. In these instances, participants tried to “push” through their fatigue to, as far as possible, perform and complete tasks (see subsection 5.5.2).

5.3.3 Loss of Spontaneity

A few participants perceived a loss of spontaneity in life as indirectly caused by MS-F. Whilst most participants did not explicitly emphasise a loss in spontaneity as an impact of MS-F; it nonetheless represented a noteworthy finding on how MS-F may impact PwMS's everyday lives. I came to this conclusion since a perceived loss of spontaneity was highly congruent within, and across, all participants' accounts of living with MS-F. Moreover, this theme provided insight into MS-F's more downstream implications for life. A perceived loss of spontaneity was most vividly conveyed through the following extract from P1's account:

> And ja, you have to plan a lot more. I used to really like being spontaneous, um, like spontaneous to go out to the movies, or spontaneously (pronounced exhalation) go out for dinner or go visit people or randomly go down to George. Um, you can't always do that because you m-might be completely fatigued. Where I might have thought like in the morning, "Ahh, this. I wanna come... go do that." And it gets to the evening and it's like, "There's no way I'm gonna be able to do that."

As this quote illustrates, P1 considered her past self (i.e. the energetic self) to be someone that could, and frequently did, participate in the world in a spontaneous fashion. In contrast, P1 regarded her present self (i.e. the fatigued self) as relatively unspontaneous in everyday life. Accordingly, MS-F appeared to imply a loss of spontaneity in life. Convergent with P1's notion, P2 regarded spontaneity to be a feature of a past life. This convergence was evident in how P2 distinguished her past and energetic self from her present and fatigued self: "I can't just on the spur of the moment drop everything, grab a bag and go out, like when I was younger. I've got to plan it…" Whilst some participants perceived MS-F as signifying a loss of spontaneity; these same participants regarded MS-F as indirectly constraining their spontaneous action. This was evidenced by P1 whose loss of spontaneity emanated from her need to avoid an unanticipated MS-F episode in the future. Here P1, by responding to a need, inevitably constrained her own spontaneity. As such, it appeared that the needs which MS-F introduced to life implied greater restrictions for spontaneity in life. Convergent with this, P2 regarded her need to manage MS-F as restricting her spontaneity in everyday life. This notion was vividly portrayed by P2 when she attributed her loss of spontaneity to enacting her need for MS-F management (see next page):

> I can’t just on the spur of the moment drop everything, grab a bag and go out, like when I was younger. I’ve got to plan it, I’ve got to plan to when I take my tablets and I’ve got to plan to when I go to sleep and all these issues, I’ve got to plan it.

The perceived loss of spontaneity which accompanied some participants MS-F was a diffused and relatively consistent FOL. Here a loss of spontaneity emanated from the needs which MS-F introduced to life. In this sense, a loss of spontaneity did not seem to be a transient occurrence that accompanied MS-F episodes. Moreover, it is important to clarify why a loss of spontaneity represented an indirect consequence of MS-F. As presented, some participants’ spontaneity was constrained by a need to accommodate future MS-F experiences. This accommodation would not have been needed if someone did not suffer from MS-F. Therefore, MS-F indirectly constrained the spontaneous action of some participants.

5.4 Participants’ Sense-making of MS-F Management

When speaking about MS-F management, participants tended to describe their participation in, and implementation of, energy maintenance strategies. From these data segments, I identified one superordinate theme representative of how participants understood MS-F management. Here I found that participants understood MS-F management as a planned accommodation of MS-F through energy maintenance. This understanding encompassed two intimately linked yet distinct themes. These themes were perceptions of: (a) MS-F management as preparatory in nature, and (b) energy maintenance as a route to MS-F management. These two themes were linked since MS-F management signified a preparation for MS-F and functioning; whilst preparation, and thus MS-F management itself, was achieved through energy maintenance. For a visual representation of how participants understood MS-F management in this study see Figure 5.3 on the next page.

Figure 5.3

Participants' Sense-making of MS-F Management

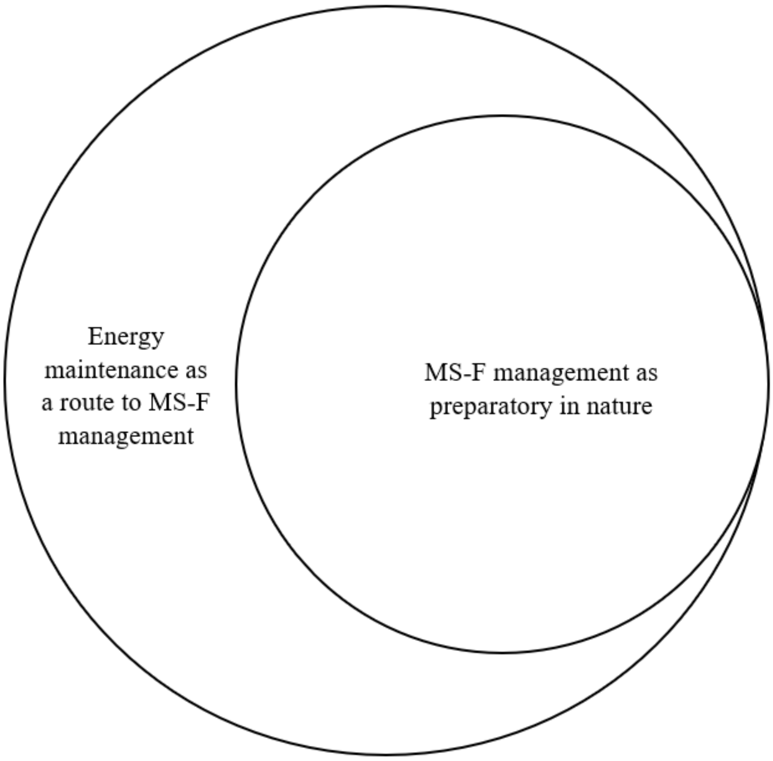

Figure 5.3. Visual illustration of the perceptions/themes (see text) characterising participants sense-making of MS-F management.

Importantly, circle overlap in Figure 5.3 does not suggest that a notion of preparation was subsumed by a perception of energy maintenance. Much rather, these two perceptions existed in parallel since they were concerned with different facets of MS-F management. In Figure 5.3, circle overlap alludes to the degree to which energy maintenance approaches were preparatory in nature. Consequently, Figure 5.3 illustrates that whilst all preparatory endeavours implied energy maintenance, all energy maintenance strategies were not preparatory in nature. With this point in mind, I now present how participants made sense of MS-F management.

5.4.1 MS-F Management as Preparatory in Nature

Most participants perceived MS-F management as preparatory in nature. That is, participants perceived MS-F management as preparing for potential MS-F episodes in the future. Moreover, preparation itself appeared to represent a safeguarding of future functioning through energy maintenance. The perception of MS-F management as preparatory in nature was most vividly expressed by P1 through a metaphor in which she likened MS-F management to child rearing:

> You always kind of have like a contingency plan in case any of that happens [i.e. a severe MS-F episode] (inhalation) it's almost like having a-a child that never grows up. You always have to take that bag around with you. The-the feeding and the nappies and whatnot, like, you always have to be cognisant of it and taking care of it.

In the above quote, P1 likened MS-F management to endlessly caring for "a child that never grows up." This illustrated that, for her, MS-F was an ever-present responsibility which necessitated continuous care. Furthermore, P1 designated continuous planning (i.e. continual preparation) as essential to accommodating any potential MS-F episode in the future. Similarly, P3 described MS-F management as being synonymous with planning ("So, managing fatigue is-is. I would say it's planning…"), whilst P2 designated her ability to endure future functioning as predicated on preparation ("…I've got various things that I need to do to make sure that I can survive the next day and that is resting…"). Moreover, most participants regarded a planned accommodation of MS-F as integral to managing MS-F in everyday life. Take as illustrative of this P3's description of how she manages MS-F:

> By planning very carefully. That's the only thing that's worked, like I said, the medication, none of that works it's only planning. You have to literally put in periods of rest, for your day and for your week, it's the, uh, only way.

Through this quote it is evident that P3 regarded preparation (through scheduled resting) as central to effectively managing MS-F. Here P3's valuation of preparation being the "only way" to manage MS-F emphasises the importance of planning for, and accommodating, MS-F in everyday life. This sentiment is echoed through participants' use of absolutist terms (e.g. "You always have to" or "it's the only thing that works") and essentialist language (e.g. "I have to", "I need to", "I must", etc.) when speaking about how they prepare for potential MS-F episodes in the future.

Participants spoke about preparing for both foreseeable and unforeseeable MS-F episodes. Here it seemed that the mere potential for experiencing MS-F in the future warranted/required preparatory measures. Furthermore, participants who perceived MS-F management as preparatory in nature considered a planned accommodation of MS-F as attainable through energy maintenance. This was evident in participants emphasising certain energy maintenance approaches as preparatory endeavours that safeguard future functioning. The energy maintenance approaches designated as preparatory in nature were energy regeneration and energy conservation (see section 5.4.2). As illustrative of this designation, consider the following quote from P1's account: "…if-if I know that I'm going to be doing something, um, ja, um… You-you'd get extra sleep the night beforehand… it's all planning and having – being prepared, is a better word for this." Through this quote, it appeared that P1 regards energy regeneration as preparatory in nature and a route by which to safeguard future functioning (i.e. to accommodate potential MS-F). In this sense then, for P1, energy regeneration signified a form of preparation. Notably, similar notions to that of P1 were espoused by most participants in this study.

5.4.2 Energy Maintenance as a Route to MS-F Management

All participants understood MS-F management as attained/realised through energy maintenance. This notion was evidenced by energy maintenance tactics (e.g. rest, sleep, or eating) being depicted as a route by which to achieve MS-F management. For participants in the present study, energy maintenance appeared to involve three distinct energy management strategies. These energy maintenance strategies were energy conservation, energy regeneration, and energy acquisition. Participants highlighted these energy management strategies as geared towards achieving certain outcomes. With respect to this, different energy maintenance strategies were emphasised as: (a) a route by which to prepare for future functioning (i.e. render future functioning more feasible/attainable), and/or (b) a route by which to facilitate ease in present functioning. In the following subsections, I present how participants perceived energy maintenance as a route to MS-F management. Here energy maintenance is reported through three subsections dedicated to energy conservation, energy regeneration, and energy acquisition respectively.

5.4.2.1 Energy Regeneration as Route to MS-F Management. Most participants perceived energy regeneration as a valuable route by which to manage MS-F. Participants conveyed this perception by designating acts which mitigate a lack of energy (i.e. sleeping, naps, or resting) as important avenues of MS-F management. A perception of energy regeneration as a route to MS-F management was most explicitly communicated through the following two quotes from P2's account:

1. "…in the evenings I have one ml of cannabis oil which helps me sleep. Because people with MS battle to sleep, we don't sleep through. And this gives me a good five hours' sleep every night which helps me to have more energy for the next day. I've been on it for about 15 months now and I can see a huge difference in what it's doing to me."
2. "…I have a good nap on a Saturday afternoon and then a Sunday afternoon. Therefore, I have regenerated myself, so I can have a bit of a longer TV session, or I can do – I do scrapbooking."

From the first quote it is evident that P2 considered energy regeneration (something induced through cannabis oil) as a route towards MS-F management. Here P2's last sentence attests to the profound effect and value that induced energy regeneration has had for her everyday functioning. Similarly, P2's second quote highlights energy regeneration as a way to preserve future functioning (i.e. to render future functioning more feasible and endurable). The notion that energy regeneration represents a route to managing MS-F was also conveyed by other participants. For example, P6 described rest as restoring his functional capacity through energy regeneration ("It's as if, after I've rested for a half an hour or hour or so, then I just have new energy then I can keep on going for the evening."), whilst P4 designated prolonged energy regeneration as a route of managing MS-F ("I manage my fatigue by making sure that every night I get eight to nine hours of sleep.").

Whilst participants perceived energy regeneration as a valuable to MS-F management; most participants considered energy regeneration to be an undependable MS-F management strategy. In respect to this, participants emphasised how sleep was an undependable energy regeneration tactic that was inconsistent in alleviating/mitigating MS-F. Moreover, participants mentioned that engaging in energy regeneration tactics was, on occasion, undesirable or unfeasible. Here the restrictions inherent to participants' everyday lives (e.g. occupational expectations) appeared to impede the feasibility of energy regeneration as a MS-F management strategy. In instances where energy regeneration was appraised as undesirable/unfeasible, energy regeneration was described as detrimental to the self.

5.4.2.2 Energy Conservation as Route to MS-F Management. All participants perceived energy conservation as a valuable strategy by which to manage MS-F. Participants conveyed this perception by speaking about how they managed MS-F by restricting their energy expenditure. This included accounts of how participants restricted energy expenditure by suspending their present functioning (e.g. resting or taking breaks) and avoiding task-performance. These two energy conservation tactics were emphasised as capable of both preserving functional ability and safeguarding future functioning. A perception of energy conservation as a route to MS-F management was most vividly articulated by P1 through the following quote:

> You wouldn't exert yourself so much if you know you're gonna be doing something else. Again, it's all planning and having – being prepared, is a better word for this. You're gonna have to conserve your energy as much as you can.

Through this quote it is apparent that P1 considered energy conservation as indispensable to her ability to function in the future. In this respect, she highlighted an avoidance of over-exertion (i.e. a restriction of excessive energy expenditure) as essential to prepare her future self for participating in the world. Convergent with P1, P3 regarded planned energy conservation as rendering her future functioning more attainable/feasible: "I have to plan my week, so if I know I want to do something on Thursday evening then I know I have to do… something less on Thursday so that I do have the energy to go there." Akin to P1 and P3, all other participants considered energy conservation as a route to MS-F management. For instance, P6 spoke about avoiding over-exertion to manage MS-F ("…I don't overextend myself"), whilst P5 suspended functioning when severely fatigued ("I say, um, 'I don't have much energy, can we just rather stay home tonight.'").

As illustrated by the quotes thus far, participants regarded energy conservation as largely valuable to their future selves. That is, energy conservation represented an important route by which to prepare for future functioning and accommodate potential MS-F episodes in future. Here the value of energy conservation in MS-F management was most meaningfully conveyed through the following story told by P5:

> …we (P5 and a friend) sat on a bench looking out at the sea, like, almost like two old people and we just, we didn't even speak, much, and I told him: "You know, we can sit here the whole day and not even say a word and it will not be a day wasted. It will be a perfect day."

This quote is illuminating since it illustrated how a day dominated by energy conservation constituted a "perfect" and worthwhile day. When this valuation was considered along with energy conservations' primary aim (i.e. to prepare for future functioning), the utility of energy conservation in managing MS-F was decidedly apparent. Nonetheless, some participants designated energy conservation tactics to be, on occasion, unimplementable. This unfeasibility seemed to emanate from constraints in daily life (e.g. occupational expectations) which rendered energy conservation unfeasible and/or potentially disadvantageous/detrimental (e.g. job loss or demotions).

5.4.2.3 Energy Acquisition as Route to MS-F Management. Most participants perceived energy acquisition as a valuable route by which to manage MS-F. When speaking about MS-F management, participants typically highlighted how they engaged in acts aimed at providing them with energy (i.e. energy acquisition tactics). These energy acquisition acts served to revitalise participants and facilitate ease in present or impending functioning. As illustrative of energy acquisition as a route to MS-F management, consider this quote from P2's account (see next page):

> And then there's lunchtime … I have my cup of tea and I have the rest of my sandwiches because I-I need the energy I need to have something to eat to keep my brain going as well because MS does tax me, it makes me tired. So, I've got to make sure my body is adequately fuelled to see me through for the rest of the afternoon.

This quote is useful since it illustrates a perceived link between energy acquisition and P2's ability to sustain functioning. Through the quote it appears that, for P2, routine energy acquisition represents an essential tactic that diminishes her need for energy. Here this essentiality of energy acquisition is evidenced through P2's semantic expressions "I need …" and "I've got to make sure…" Moreover, bodily revitalisation (i.e. nourishment) is presented as a tactic by which to safeguard functioning when experiencing MS-F and its mental impairments. Consistent with P1, P5 also regarded bodily revitalisation to be a tactic which may safeguard functioning:

1. "I'm in danger of drifting off. So that's the time that I start up and I get up and walk around a bit and ja, just then I try to wake up again. But, ja I don't understand it really but sometime after that the, the fatigue um, goes away…"
2. "Of course, the heat also, um, really takes the energy out of you and ja, so then I'll… walk around a bit to, to get the blo-blood flowing again…"

From the first quote it is evident that P5 lacks some insight into why fatigue dissipates following brief ambulation. Nonetheless, he presents brief ambulation as capable of dissipating MS-F. Emphasis here is on "capable" since his use of the term "try" suggests that brief ambulation is not consistently effective at dissipating MS-F. Also, when considering the second quote, it is evident that brief ambulation represents a revitalisation tactic capable of redressing P5's need for energy. Convergent with P2 and P5, P1 considered revitalisation to be an energy acquisition tactic capable of managing MS-F. She highlighted how she typically carries around "high energy snacks or drinks" and uses medication to curtail MS-F's severity and to safeguard functioning. With respect to medication, P1 highlighted methylphenidate use to be a tactic by which she could acquire energy and “medicate it (i.e. MS-F) away”. Likewise, P4 designated medicinal interventions to be valuable since medication could partially redress her lack of energy.

As a whole (i.e. when considering all narrative accounts), participants described energy acquisition as enacted through tactics such as routine eating, hydration, ingesting high energy food/drinks, taking energy inducing medicine, and brief ambulation. Notably, different participants adopted different combinations of these energy acquisition tactics. Moreover, the perceived utility of medication to redress a lack of energy was, at best, a toss-up. That is, whilst some participants regarded medication as an effective tactic by which to manage MS-F; other participants perceived medication as ineffective in, or detrimental to, MS-F management. Interestingly, energy acquisition appeared to be a MS-F management strategy which participants largely relied on when energy regeneration and energy conservation were deemed to be contextually unfeasible/inappropriate.

5.5 Participants’ Sense-making of Coping with MS-F as a FOL

When speaking about coping, participants typically spoke about “those things” that permit them to live life with MS-F, and how they have managed to live with MS-F. From these accounts, I identified one superordinate theme which reflected how participants understood coping with MS-F. This superordinate theme was that coping with MS-F signified an acceptance of a fatigued self and life. Here this understanding comprised two linked themes. These themes were perceptions that coping involved: (a) an acceptance of MS-F and MS-F’s restrictions on life, and (b) an acceptance of MS-F as a FOL. I visually illustrate these perceptions that typified participants’ sense-making of coping in Figure 5.4 on the next page.

Figure 5.4

Participants Sense-making of Coping with MS-F

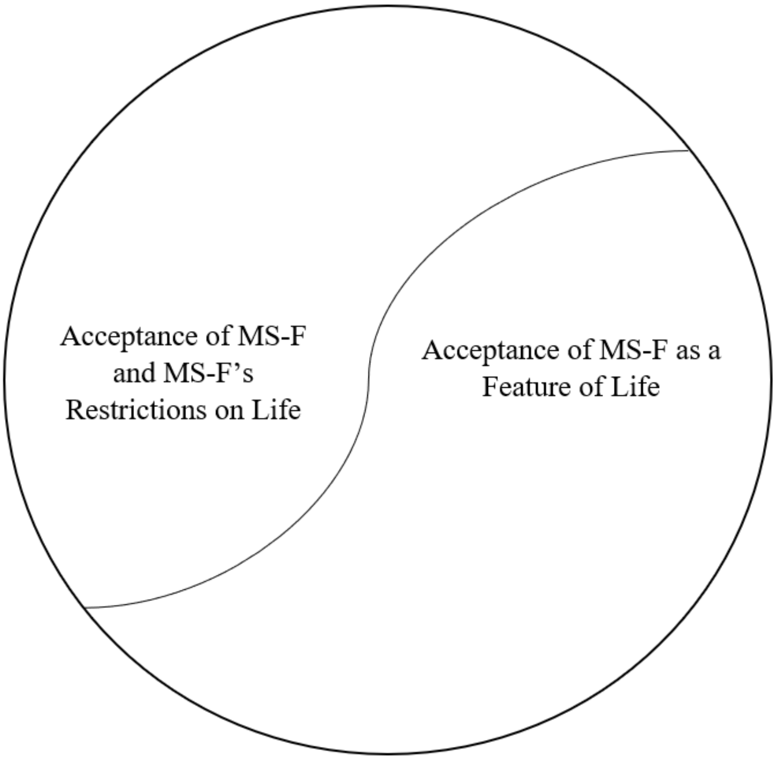

Figure 5.4. Visual illustration of the perceptions/themes (see text) characterising participants sense-making of coping with MS-F.

It is important to note the curved line intersecting the circle in Figure 5.4. This curved line is intended to imbue the illustration with motion since acceptance appeared to be a dynamic and ongoing process. Having provided an reductionist overview of the findings in Figure 5.4, I now report my findings on how participants understood coping with MS-F.

5.5.1 Acceptance of MS-F and MS-F's Restrictions on Life

Most participants perceived coping to involve an acceptance of MS-F and MS-F's restrictions on life. This perception was most explicitly articulated by P4 in speaking about how she copes with MS-F:

> How do I live with it? The first thing is I don't-uh, I don't ignore it and I try to do what I can. Secondly, um, it is only through experience over the years that I've learnt to deal with the negatives associated or-or society related um, um, view of fatigue and I've learnt how to live with it … That's probably my best answer I can give you. So, I've learnt, I've learnt

> how to develop the tools to help me not feel bad about what's happening to me. It's not, it's not my fault.

There are two important points to note from P4's quote. Firstly, P4 designated the prioritisation and acknowledgement of MS-F as enabling her to live with MS-F. In this respect, it seemed that the conscious acceptance of MS-F – as a feature of self and life – represented a means to cope with MS-F. Secondly, P4 highlighted how she can live with MS-F by processing her feelings of guilt. This includes guilt which arose from being an MS-F sufferer as well as guilt emanating from societal misperceptions of MS-F. When considering this description alongside P4's concluding statement ("It's not, it's not my fault."), it seemed that an acceptance of MS-F as uncontrollable enabled P4 to cope with MS-F. Congruent with P4's perception, other participants regarded an acceptance of MS-F's restrictions on life as important in coping with MS-F. As illustrative of this notion, consider how P3 talked about coping with MS-F: "You can't say yes to everything; you can't do all of it, just realising that. …. Just realising that it's okay to say, no, and it's okay not to do everything." This quote reveals how P3 regarded an acceptance of her restricted functional ability as how she copes with MS-F. That is, it appeared that an acceptance of MS-F's restrictions on life signified coping itself. Moreover, P3's assertion "just realising that" posits an acceptance of MS-F's restrictions on life as valuable to coping with MS-F. Consistent with P3, other participants considered an acceptance of MS-F's restrictions on life to be implicated in coping. For instance, P6 deemed an acceptance of a restricted capacity to participate in the world to signify coping (…and that's what I do. That's lifestyle, accept what I can't do and get somebody to do it, or leave it and see that I don't overextend myself."), whilst P1 highlighted an acceptance of a loss of independence as implicated in coping with MS-F:

> I've learnt to ask for help, um, I-I was always a very independent person and would just do it myself. I've had to kind of let that go and if-if I need help, I need to, I have to ask for it and I-I had to start asking.

The previous quote illustrates how P1 regarded a greater dependence on others as essential since it facilitated demand fulfilment in life, despite a loss of functional capacity. Accordingly, P1's acceptance of a loss of independence thus signified a way to cope with MS-F's restrictions on life.

It should be noted that most participants found it difficult to accept MS-F and its restrictions on life. With reference to this difficulty, P3 and P4 considered the acceptance of MS-F and its restrictions on life as a continuous and cyclical process. This perpetual and cyclical process of acceptance is most vividly demonstrated through the following quote from P3's account:

> Um, but ja, there's a lot of guilt in-involved and it-it's an ongoing process, it's not that you reach a point where you say: "You know what, I can't and that's okay." It's a spiral, you always go back to feeling guilty and having to remind yourself, "You know what, it is okay. You can feel tired, you have a reason." It-it's continuous, it's a cycle…

As the above quote illustrates, acceptance was perceived as an ongoing and dynamic process as opposed to a realisation that was reached and maintained. Here an acceptance of MS-F and its restrictions appeared to be something that participants came close to but did not embrace. Similar sentiments of not having fully accepted MS-F and its restrictions on life were also shared by P4 and P5. Notwithstanding this, P2 described how the passage of time assisted her in coming to an acceptance of a fatigued self and life.

5.5.2 Acceptance of MS-F as a Feature of Life

Most participants perceived coping to require an acceptance of MS-F as a FOL. With an acceptance of MS-F as a FOL, I refer to an acceptance of a need to live life despite MS-F. As exemplative of this notion, consider the following quote from P1's account:

> Um, you have to deal with it (MS-F); you don't have a choice you just have to… I mean it's generally like a – in life there's things you have to do, you just have to have it done so you, you just cope. You push through, you have to.

From this quote, it is evident that P1 regarded an acceptance of a need to live life despite MS-F as both involuntary and essential. Here an acceptance of MS-F as a FOL was appraised as being essential and involuntary since essential demands of life had to be met (e.g. responsibilities and/or needs). To meet these essential demands of life, P1 enforced functioning by pushing through her fatigue. Here it seemed that "pushing through" MS-F provided a route for P1 to live life despite MS-F. Accordingly, enforced functioning (i.e. pushing through MS-F) appeared to represent the behavioural enactment of having accepted a need to live life despite MS-F.

Convergent with P1, other participants also perceived coping as requiring an acceptance of MS-F as a FOL. Take for instance P6, who appeared to have accepted MS-F as an inalienable feature of his life ("…I didn't know what to do and then I just tried to live with it.") and remains committed to living life despite MS-F ("…you try regardless, you can't pay people for every little thing that needs to be done. Um, so yes, fight on regardless."). Similarly, P5 accepted self-enforced functioning as essential to fulfilling demands in life despite MS-F ("I just, I just go on with life. It's- These things must be done, and I try to do it as best as I – These are the daily tasks and I try to do it a best as I can."), whilst P4 was resolutely committed to living life irrespective of MS-F ("…it's all about attitude and so I just generally get on with it."). Furthermore, other participants also regarded enforced functioning – akin to P1 – as the behaviour enactment of accepting MS-F as a FOL. Take as representative of this notion the following quote from P4's account:

> …I think general fatigue; I just get on with it, to be honest. I-I don't, I don't complain. I know I'm tired or I'm fatigued. I mean I'm not talking extreme now; I'm talking like maybe mild to moderate fatigue. I just kind of get on with I-I use my, my attitude and my mental strength to get on with it.

Through this quote, P4 designated a reliance on willpower as being needed to enforce functioning when mildly/moderately fatigued. In enforcing functioning, P4 was keenly aware of being fatigued, yet remained committed to living life despite her MS-F. Here this commitment to living life despite MS-F appeared to represent a behavioural enactment of an acceptance of MS-F as a FOL. Notably, participants typically highlighted "pushing through" MS-F (i.e. enacting their acceptance of MS-F as a FOL) as a route to wish fulfilment, goal attainment, and essential task completion (e.g. meeting needs and obligations). Nonetheless, participants described enforced functioning as being arduous and demanding in nature. That is, pushing through had the potential to severely exhaust some participants. Additionally, some participants highlighted ensured functioning to be unfeasible or unimplementable in certain instances (e.g. when severely fatigued).

5.6 Conclusion

In this chapter, I reported on the results of my IPA analysis of six participants' accounts of living with MS-F. The sample in the present study was relatively homogenous since it consisted of white participants from a largely middle-class background. Whilst most participants suffered from depression, these participants could distinguish between MS-F and depression-related fatigue. In this chapter, I reported MS-F as being an important and meaning laden phenomenon within participants' lives. With respect to this, I identified participants' lived experiences of MS-F to encompass several meanings. As reported, participants understood MS-F as a symptom through its symptomatic features as a lack of energy that was ever-present, yet inconsistent in life. Additionally, participants regarded MS-F to manifest through subjective mind-body phenomena. Furthermore, MS-F's impacts on everyday life were understood as a restricted capacity to participate in the world. This understanding encompassed perceptions of a restricted functional capacity and losses in both independence and spontaneity. Moreover, participants understood MS-F management as a planned accommodation of MS-F through energy maintenance. Here participants espoused notions of MS-F management being preparatory in nature and being attained through energy maintenance. Lastly, participants understood coping with MS-F as signifying an acceptance of a fatigued self and life. An understanding which implied an acceptance of MS-F and MS-F's restrictions on life, and an acceptance of MS-F as a FOL. Overall, the present study's results provided insight into the shared/typical understandings which underscored participants' experiences of MS-F as a FOL. That is, the present study elucidated what MS-F signified and implied for participants and their lives.

Chapter 6: Discussion

In this study, I sought to explore the lived experiences of MS-F amongst PwMS living in the WC. The RQ was as follows: “What are the perceptions and meanings of living with MS-F amongst PwMS in the WC?” Thus, the primary aim of the study was to explore and interpret how PwMS in the WC perceive and make sense of living with MS-F. I attempted to achieve this through an IPA analysis geared at attaining four objectives. These objectives were the exploration and interpretation of PwMS’s accounts of: (a) MS-F as a symptomatic experience, (b) MS-F’s impacts on daily life, (c) MS-F management, and (d) coping with MS-F. In this chapter, I discuss the research findings and consider my results in relation to existing literature on how PwMS understand MS-F. This discussion is dedicated to underlining and clarifying those perceptions salient in, and relevant to, the aforenoted objectives. Following a discussion of the research findings, I underscore and unpack the theoretical implications and practical utility of the research findings. Hereafter, I present and elaborate on the strengths and limitations of this study, whereafter I propose recommendations for future inquiry into MS-F.

6.1 The Meaning of MS-F as a Symptomatic Experience

PwMS in the present study understood MS-F as a symptomatic experience through MS-F’s symptomatic features. Participants perceived these symptomatic features to be: (a) a lack of energy, (b) an ever-present inconsistency of life, and (c) a subjective mind-body phenomenon. Accordingly, to experience MS-F means that one experiences a persistent, yet variable, state of energetic deprivation that manifests through physical and/or mental phenomena. This finding is discussed through its constituent perceptions (as listed above) in the ensuing subsections.

6.1.1 MS-F as a Lack of Energy

PwMS in this study perceived a lack of energy as a characteristic feature of MS-F’s symptomatic experience. This lack of energy was found to be a pronounced, severe, and highly undesirable occurrence. The finding that participants perceived a lack of energy as central to MS-F’s symptomatic experience aligns with other qualitative findings on MS-F (Flensner et al., 2003;

Mills & Young, 2008; Newton et al., 2020; Olsson et al., 2008; Stuifbergen & Rogers, 1997), and converges with how MS-F has been conceptualised in the broader literature (Krupp, 1998; Leocani et al., 2008; Lerdal et al., 2007, MSC, 1998). Likewise, the identification of a lack of energy in MS-F as pronounced and severe is consistent with prior research findings on MS-F (Flensner et al., 2003; Mills & Young, 2008; Olsson et al., 2008; Stuifbergen & Rogers, 1997). As such, existing literature supports the finding that a perceived lack of energy is integral to how PwMS understand MS-F as a symptom. Accordingly, to experience MS-F therefore means that one experiences a substantial energetic deficiency.

Despite converging with existing literature, the present study identified two more nuanced findings. The first nuanced finding was that a lack of energy in MS-F involved both a physical and a mental dimension. This finding diverges from reports that a lack of energy is a solely physical resource depletion (Flensner et al.'s 2003; Newton et al., 2020; Olsson et al., 2008), and affirms the MSC's (1998) definition of MS-F as: "A subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activities" (p. 2). The finding that a lack of energy involves both a physical and mental dimension suggests that researchers/HCPs should not assume "energy" to be a solely physical concept in MS-F. The second nuanced finding was that PwMS in this study could distinguish MS-F from fatigue in depression. Whilst both these types of fatigue were characterised by a lack of energy, MS-F was perceived as distinct since it was not typified by a loss of motivation or accompanied by marked despair. Notably, a perceived lack of energy may be espoused in relation to other "types" of fatigue besides MS-F. This seems possible since a lack of energy appears to be central to fatigue in other chronic conditions such as RA (Feldthusen et al., 2013) and MND (Gibbons et al., 2013). Nonetheless, whilst energy deprivation is implicated in general fatigue (Aaronson et al., 1999; Shen et al., 2006), it is the severe lack of energy in MS-F which seems to distinguish MS-F from general fatigue.

6.1.2 MS-F as an Ever-present Inconsistency of Life

Perceiving MS-F as an ever-present inconsistency of life comprised two notions. These notions were perceptions of MS-F as: (a) an ever-present FOL, and (b) as an inconsistency in life.

6.1.2.1 MS-F as an Ever-present Feature of Life. Participants perceived MS-F as an ever-present FOL in that MS-F was regarded as enduring throughout life. This finding converges with findings of other qualitative research on MS-F (Flensner et al., 2003; Olsson et al., 2005; Stuifbergen & Rogers, 1997), and is consistent with reports that MS-F is a chronic symptom (Mills & Young, 2008; Whitaker & Mitchell, 1997). Thus, it appears that MS-F may signify an ever-present phenomenon in PwMS’s lives. In this respect, MS-F appears to constitute a recurrent phenomenon that typifies the everyday lives of MS-F sufferers.

Besides confirming existent theory on MS-F, the present study identified MS-F’s ever-presence to be a substantial burden in the lives of participants. Here MS-F’s ever-present nature posited MS-F as a symptom which may be lived with, but not controlled or consistently controlled (i.e. alleviated/avoided). This finding is important since it designates: (a) reliable MS-F alleviation/avoidance as beyond the ability of PwMS, and (b) MS-F experiences as an unavoidable reality for MS-F sufferers. Given these implications, a perception of MS-F as an ever-present FOL may be useful in developing interventions which target MS-F. By recognising/acknowledging MS-F as an inevitable and largely uncontrollable symptom; interventions may exclude less feasible approaches of wellbeing promotion for more feasible ones. In theory this may take the form of, for example, psychoeducation targeted at MS-F sufferers which: (a) deprioritises personal accountability when promoting MS-F management strategies, and (b) promotes an acceptance of MS-F as an unavoidable FOL.

6.1.2.2 MS-F as an Inconsistency in Life. Besides perceiving MS-F as an ever-present FOL, participants perceived MS-F as an inconsistency in life. That is, participants considered MS-F to be an episodic symptom which varied in its momentary presence and severity. This finding is consistent with Mills and Young’s (2008) finding that MS-F is a chronic yet temporal symptom, as well as reports that MS-F experiences vary in severity (Comi et al., 2001; Johnson et al., 2004; Krupp et al., 2010; Leocani et al., 2008). Furthermore, the finding that MS-F's onset/aggravation is largely anticipatable yet partially un-anticipatable is congruent with the broader literature on MS-F (Comi et al., 2001; Johnson et al., 2004; Krupp et al., 2010; Leocani et al., 2008). Consequently, the finding that MS-F constitutes an inconsistency in life affirms the findings of former MS-F researchers. Nonetheless, there was one discrepancy between the present finding and the broader literature on MS-F. Whereas literature suggests that MS-F onset and aggravation follows certain patterns over the course of a day (Comi et al., 2001; Johnson et al., 2004; Krupp et al., 2010; Leocani et al., 2008); MS-F followed highly individualised patterns for participants in this study. Thus, whilst MS-F onset and aggravation may follow certain patterns; these patterns appear to be subject to some interpersonal variation.

The perception that MS-F is inconsistent in life suggests that MS-F is a chronic symptom that is always fluctuating. By this I mean that MS-F's presence is reversible, and its severity is changeable (albeit beyond the control of MS-F sufferers). This implication is noteworthy since it may facilitate the refinement of existent definitions of MS-F. By regarding inconsistency as a feature of MS-F, one may define MS-F [akin to Mills and Young (2008)] beyond a mere description of MS-F's subjective experience. Such an expanded description could assist in providing more tangible parameters to existing definitions of MS-F [such as those by Leocani et al. (2008), Lerdal et al. (2007), and the MSC (1998)], and diminish ambiguity surrounding MS-F as a concept.

6.1.3 MS-F as a Subjective Mind-body Phenomenon

Participants perceived MS-F to manifest as a subjective mind-body phenomenon. This manifestation involved physical phenomena and mental alterations which emanated from a lack of energy. The finding that MS-F manifested through subjective mind-body phenomena approximates research findings of other MS-F researchers (Flensner et al., 2003; Moriya & Kutsumi, 2010; Smith et al., 2015). Moreover, the specific physical and mental involvements/expressions of MS-F identified in this study correspond to those observed in other MS-F studies (Blaney & Lowe-Strong, 2009; Flensner et al., 2003; Johnson et al., 2004; Mills & Young, 2008; Newton et al., 2020; Olsson et al., 2008; Smith et al., 2015; Stuifbergen & Rogers, 1997). As such, the broader literature on MS-F affirms the finding that MS-F constitutes a subjective mind-body phenomenon. Accordingly, it seems that to experience MS-F may mean to experience certain intrapersonal phenomena.

Despite being consistent with the broader literature, a perception of MS-F as a subjective mind-body phenomenon was characterised by two more nuanced findings. The first nuanced finding was that MS-F's intrapersonal manifestation was idiosyncratic and varied between participants. This finding does not suggest that the MS-F's manifestation will never be consistent between MS-F cases. Much rather, this finding posits that MS-F's manifestation may vary between MS-F cases. That is, it seems plausible that MS-F may express through a myriad of physical phenomena and mental alterations. Phenomena and alterations which may, or may not, be applicable to different PwMS's symptomatic experiences of MS-F. The second nuanced finding was that mind-body phenomena distinguished participants' fatigued selves from their non-fatigued selves. Here it seemed that PwMS came to recognise their fatigued selves through MS-F's subjective mind-body phenomena. This finding may be valuable to the development of interventions targeting MS-F. By coaching MS-F sufferers to recognise their fatigued selves through MS-F's mental and physical involvements, one may foster, within PwMS, a conscious awareness of their momentary energy reserves. Said conscious awareness may provide MS-F sufferers with insight into whether to enforce functioning or engage in MS-F management. Something which may [in accordance with the APA (2020) and Audulv et al. (2016)] facilitate coping by serving as a cognitive strategy for dealing with MS-F.

6.2 The Meaning of MS-F for Everyday Life

In the present study, participants understood MS-F as restricting their capacity to participate in the world. Participants perceived this restriction as occurring through a restricted functional capacity, a loss of spontaneity, and a loss of independence. Moreover, it appeared that negative emotions and negative appraisals of life emanated from participants' restricted capacity to participate in the world. The finding that participants understood MS-F as restricting one's capacity for participating in the world approximates Olsson et al.'s (2005) and Flensner et al.'s (2003) findings. Moreover, this finding converges with reports that fatigue restricts PwoCCs' lives in RA (Feldthusen et al., 2013; Thomsen et al., 2015), ME (Strassheim et al., 2021), and IBD (Czuber-Dochan et al., 2013). Existing literature (Flensner et al., 2003; Moriya & Kutsumi, 2010; Newton et al., 2020) is also consistent with the finding that negative appraisals and emotions emanate from a restricted capacity to participate in the world. Therefore, the finding that MS-F signified a restricted capacity to participate in the world is consistent with prior research on MS-F and chronic fatigue. As such, PwMS may deem their functioning in everyday life to be typified by MS-F induced restrictions. That is, it appears that living with MS-F means that one lives a life where everyday possibilities and actions are delimited. Moreover, it seems plausible that these delimitations may lead to undesirable emotions and negative appraisals of life.

The finding that participants understood MS-F to restrict their participation in the world has important implications for interventions seeking to promote MS-F sufferers' wellbeing. Here this finding suggests that interventions should aim to: (a) lessen/reduce the degree to which MS-F restricts participation in the world, and (b) foster a greater capacity for self-determination in everyday life. In practice, this may take the form of interventions seeking to equip MS-F sufferers with greater MS-F management and coping skills. Nonetheless, expectations regarding the efficacy of such interventions should be tempered. Whilst it is plausible that such interventions could assist MS-F sufferers to participate in the world more fully; it seems unlikely that such interventions would eliminate MS-F's restrictions in life.

Thus far I have discussed, in broader terms, the finding that MS-F signified a restricted capacity to participate in the world. Given this, I now foster greater insight into this meaning by discussing its constituent perceptions.

6.2.1 Restricted Functional Capacity

PwMS in this study perceived MS-F as restricting their functional capacity. This finding converges with reports of MS-F restricting, limiting, and disrupting PwMS's activities (du Plooy & Pretorius, 2014; Moriya & Kutsumi, 2010; Smith et al., 2015; Stuifbergen & Rogers, 1997). Given this convergence, it seems that MS-F sufferers' everyday lives may be typified by a restricted functional capacity. Thus, to live with MS-F appears to mean that one lives a life characterised by a limited ability to perform and complete tasks/activities. Despite affirming preceding research findings on MS-F's impacts on daily life; the present study identified two notable insights into how participants comprehend their restricted ability to function. The first insight was that the functional restrictions emanating from MS-F may signify MS-F's most prominent and detrimental impact on everyday life. This insight suggests that the functional restrictions emanating from MS-F may be a central concern within MS-F sufferers' daily lives. Moreover, this insight also suggests that interventions seeking to enhance MS-F sufferers' wellbeing should aspire to mitigate MS-F's functional restrictions. The second insight was that MS-F's restrictions to functional capacity appeared to be threefold. Here it seemed that MS-F restricted PwMS's functional capacity by: (a) inhibiting functioning, (b) preventing extensive functioning, and (c) by suspending the feasibility of future functioning. I discuss these notions in further detail in the ensuing subsections.

6.2.1.1 MS-F Induced Functional Inhibition. Participants in the present study perceived MS-F to inhibit their functioning within everyday life. Here MS-F was highlighted as capable of subverting participants' present functioning, task-performance, wish fulfilment, and goal attainment. Moreover, MS-F could become so severe that functioning and task-performance became unfeasible or untenable. The finding that MS-F was perceived to inhibit functioning converges with findings from other MS-F researchers (Flensner et al., 2003; Kayes et al., 2011; Mills & Young, 2008; Moriya & Kutsumi, 2010; Stuifbergen & Rogers, 1997). Likewise, PwoCCs have reported functional disruptions to emanate from fatigue in conditions such as endometriosis (DiBenedetti et al., 2020), ME (Strassheim et al., 2021), and MND (Gibbons et al., 2013). Taken together, it seems plausible that PwMS may perceive functional inhibition to be a phenomenon that typifies life with MS-F. Accordingly, to live with MS-F appears to mean that one lives a life characterised by functional inhibition.

Participants' understanding of an MS-F induced functional inhibition was characterised by some complexity and nuance. With regards to complexity, the present study found that participants' functional inhibition emanated from a lack of energy. Additionally, it seemed that the degree to which MS-F inhibited functioning changed with changes in MS-F's severity. These findings suggest that MS-F's inhibitory potential/power is predicated on PwMS's momentary energy reserves. This inference is congruent with participants' holistic understanding of MS-F and suggests that MS-F's inhibitory potential varies between MS-F episodes. In addition to complexity, the present study identified one nuanced characteristic of an MS-F induced functional inhibition. This characteristic was that MS-F appeared to inhibit functioning irrespective of the nature of task-performance (i.e. whether a task was demanding/undemanding). Said characteristic suggests that MS-F inhibits broader functioning in daily life as opposed to the performance of specific tasks/activities. Moreover, this characteristic implies that MS-F's functional inhibition can affect even those rudimentary and mundane tasks typifying everyday life. Here these inferences posit MS-F's ability to inhibit functioning as a debilitating and pervasive feature of MS-F sufferers' realities. Given this salience it is advised that researchers, HCPs, and interventionists working with MS-F sufferers remain cognisant of MS-F's potential to inhibit functioning. This cognisance is important since it denotes a considered concern for MS-F sufferers' needs and wellbeing. Moreover, said cognisance could also enhance the ability of researchers, HCPs, and interventionists to achieve their desired outcomes when working with MS-F sufferers.

6.2.1.2 Unfeasibility for Extensive Functioning in Everyday Life. Participants perceived MS-F as preventing extensive functioning (i.e. diffuse task-performance) within their everyday lives. Here participants regarded their ability to comprehensively participate in the world as subverted and restricted through their limited energy reserves. This finding is congruent with MS-F sufferers' reports that MS-F undermines their functioning across various aspects of daily life. This includes functioning pertaining to their personal, domestic, social, family, and occupational lives (Barak & Achiron, 2006; Flensner et al., 2003; Johnson et al., 2004; Jongbloed, 1998; Malcomson et al., 2008). This congruence provides some circumstantial support to the finding that MS-F is perceived to prevent extensive functioning in life. In essence, the present finding suggests that living with MS-F means living with a restricted ability to function in daily life. Moreover, it seems that MS-F sufferers' lives are typified by unmet/abandoned tasks, goals and wishes.

The finding that MS-F prevents extensive functioning was marked by two more nuanced findings. The first nuanced finding was that participants deemed extensive functioning to be perpetually unfeasible within their lives. The participants emphasised how their inability to diffusely participate in the world persisted irrespective of MS-F's momentary presence/absence. In theory, this finding suggests that extensive functioning constitutes an unattainable ideal within the lives of MS-F sufferers. As such, those working with MS-F sufferers should consider to what extent their requests and activities could be overwhelming/demanding for MS-F sufferers. For example, researchers should consider the extent to which their research would affect, and be affected by, MS-F sufferers' limited energy reserves. The second nuanced finding was that participants prioritised essential task-performance and deprioritised inessential task-performance. This finding suggests that whilst needs, responsibilities, and obligations may be met despite MS-F; MS-F typically prevents PwMS from fulfilling their goals, wishes and desires. Here it appears that MS-F, by preventing extensive functioning, ultimately leads to MS-F sufferers living a less fulfilled life.

6.2.1.3 Unassured Future Functioning. The last way in which MS-F was perceived to restrict functional capacity was by suspending the feasibility of future functioning. Participants' future functioning appeared to be predicated on whether MS-F would/wouldn't be experienced in the envisioned future; something which participants could only appraise with the arrival of the envisioned future, since MS-F episodes are partially unforeseeable. The finding that MS-F made participants' unassured of their ability to function in the future is most comparable to Stuifbergen and Rogers' (1997) theme "pervasive impact of fatigue on life" (p. 5). Whilst this theme is different from the perception identified in this study, both findings shared a common feature. This commonality was that a mere potential for future MS-F experiences determined how PwMS engaged with the world. Thus, there is some circumstantial evidence supporting the finding that MS-F suspends the feasibility of future functioning. Accordingly, it appears that to live with MS-F means to live with a future that is inherently uncertain and flexible.

The finding that MS-F suspends the feasibility of future functioning has some important theoretical implications. This finding suggests that MS-F sufferers anticipated/planned engagements in the world are tentative and conditional at best. Moreover, the finding indicates that any involvement in anticipated/planned engagements are determined by MS-F sufferers' intrapsychic state at the time of the engagement. As such, it seems that unmet obligations/commitments may typify the lives of MS-F sufferers. Particularly those obligations/commitments which MS-F sufferers appraise as being less essential or inessential. Deductive reasoning suggests that unmet obligations/commitments in everyday life could lead to unintended negative outcomes. For instance, if MS-F sufferers frequently abandon planned social endeavours over unanticipated MS-F; it is conceivable that some social relations would deteriorate. Such negative outcomes could be mitigated (at least in part) by promoting an awareness of how future functioning is unassured for MS-F sufferers amongst noteworthy people in PwMS's lives. This includes, for example, MS-F sufferers' family members, significant others, friends, work colleagues and employers. By informing such individuals of the unassured nature of future functioning, one could foster greater leniency and flexibility in the requirements/expectations placed on MS-F sufferers. Moreover, this leniency and flexibility could serve as a resource for MS-F sufferers and assist them to better manage, and cope with, MS-F.

6.2.2 Loss of Independence

PwMS in the present study perceived MS-F to result in a loss of independence within everyday life. This loss of independence could be so pronounced that participants lost self-sufficiency in performing mundane and relatively undemanding tasks of life. In these instances, participants considered a reliance on others as essential/necessary to complete tasks. The present finding corresponds to Flensner et al.'s (2003) findings that MS-F sufferers perceived themselves as helpless and dependent on others. This correspondence lends some credibility to the finding that PwMS perceive MS-F as subverting independence. Here the present findings suggest that a life with MS-F signifies a life with diminished autonomy.

The loss of independence identified in this study was characterised by some nuance and complexity. A nuanced finding was that the degree to which MS-F constrained independence varied. Whilst some participants perceived within themselves a loss of independence, regardless of the nature of a task; other participants held this perception only in relation to demanding task-performance. This finding suggests that MS-F sufferers' loss of independence may exist on a continuum and is subject to variation. Thus, whilst a loss of independence may be a salient and diffused phenomenon for some PwMS, a loss of independence may be a relatively milder and task-specific phenomenon for others. Furthermore, the present study identified two more intricate findings that clarified the pervasiveness of a loss of independence in participants' lives. Firstly, participants did not perceive a loss of independence in relation to the performance of essential tasks. Much rather, participants attempted to push through MS-F so that essential functions could be fulfilled despite MS-F. This suggests that a loss of independence may be actively denied and consciously resisted when tasks are appraised as essential. The second, more intricate, finding was that a loss of independence was a temporary and reversible phenomenon. This finding is noteworthy as it suggests that a loss of independence is not inherent to MS-F sufferers themselves. Much rather, it appears that a diminished autonomy is a here-and-now phenomenon that accompanies MS-F episodes.

Importantly, a greater reliance on others provided participants with a way by which to complete their everyday tasks despite MS-F. In theory, this finding suggests that interventions targeting MS-F sufferers should: (a) normalise and encourage PwMS to rely on others when fatigued, and (b) foster an acceptance of a loss of independence. It seems plausible that such interventions could enhance MS-F sufferers' wellbeing when considering the present study's findings in a holistic manner.

6.2.3 Loss of Spontaneity

Some participants perceived their everyday lives to be typified by a loss of spontaneity. This loss of spontaneity appeared to emanate from attempts at accommodating future MS-F episodes. MS-F indirectly constrained spontaneity by introducing the management of future MS-F episodes as a need. The present finding is congruent with research that reports a structured/planned approach to life as valuable in MS-F management (Blaney & Lowe-Strong, 2009; Flensner et al., 2003; Johnson et al., 2004; Malcomson et al., 2008; Moriya & Kutsumi, 2010). Such research findings are antithetical to a notion that spontaneity is typically feasible within MS-F sufferers' lives. That is, if MS-F management involves a planned/structured approach to life; such a planned/structured approach to life would imply a loss of spontaneity. As such, it appears that MS-F sufferers may perceive their everyday lives to be characterised by a lack of spontaneity. Consequently, to live with MS-F seems to mean that one lives with needs that delimit spontaneous action. Nonetheless, further research is needed to confirm/disaffirm the present finding. Particularly, since a loss of spontaneity, whilst congruent with all participants' accounts, was not explicitly mentioned by most participants.

A loss of spontaneity was characterised by one nuanced feature. This nuanced feature was that a loss of spontaneity was an overarching and relatively consistent FOL. This finding suggests that a loss of spontaneity may be a typical and prominent concern for certain MS-F sufferers. As such, spontaneity might be a useful target for psychological interventions seeking to enhance MS-F sufferers' wellbeing. For instance, an intervention may seek to promote an acceptance of a loss of spontaneity amongst MS-F sufferers. Something which could, in accordance with the APA (2020) and Audulv et al. (2016), serve as a mental approach for coping with MS-F.

6.3 The Meaning of MS-F Management

Participants understood MS-F management as a planned accommodation of MS-F through energy maintenance. This understanding involved two perceptions, namely: (a) a perception of MS-F management as preparatory in nature, and (b) a perception of energetic maintenance as a route to MS-F management. I discuss each of these perceptions in the following subsections.

6.3.1 MS-F management as Preparatory in Nature

PwMS in the present study perceived MS-F management as the preparation for future MS-F experiences. Here preparation appeared to accommodate future MS-F and safeguard future functioning. The finding that MS-F management is preparatory in nature converges with research reporting a structured/planned approach to life as valuable in MS-F management (Blaney & Lowe-Strong, 2009; Flensner et al., 2003; Johnson et al., 2004; Malcomson et al., 2008; Moriya & Kutsumi, 2010). Moreover, the present finding is also consistent with PwoCCs' reports that planning/prioritisation is valuable to MS-F management in RA (Feldthusen et al., 2013), MND (Gibbons et al., 2013), IBD (Czuber-Dochan et al., 2013), and cancer (Magnusson et al., 1999). As such, the broader literature supports the finding that MS-F management centres around preparation. Accordingly, MS-F management may, in essence, signify a preparation for inevitable MS-F experiences in the future.

The present study also identified two nuanced findings which further illuminates what preparation constitutes within PwMS's everyday lives. The first nuanced finding was that whilst MS-F management implied preparation, preparation itself was concerned with energy maintenance. This suggests that preparation is the goal/intent of MS-F management which becomes realised through energy maintenance. The second nuanced finding was that preparation was deemed to be essential to accommodating MS-F and safeguarding functioning. This essentialist valuation suggests that preparation may be: (a) a typical feature of PwMS's everyday lives, and (b) central to PwMS's everyday functioning. This inference is consistent with the finding that preparation was a continuous process which sought to accommodate both foreseeable and unforeseeable MS-F. Consequently, preparation may denote a continuous endeavour within MS-F sufferers' lives.

The theme "MS-F management as preparatory in nature" posits preparation as salient in MS-F management. As such, interventions teaching MS-F sufferers how to prepare for MS-F may be valuable and warranted. Nonetheless, the overall efficacy of such an intervention should not be overestimated. As discussed, MS-F is an ever-present FOL that is largely beyond the control of MS-F sufferers. Therefore, whilst the proposed intervention could enhance MS-F management, it seems unlikely that said intervention would permit MS-F sufferers to dependably avoid MS-F.

6.3.2 Energy Maintenance as a Route to MS-F Management

PwMS perceived MS-F management as involving energy maintenance which appeared to involve three energy maintenance strategies. These energy maintenance strategies were energy regeneration, energy conservation and energy acquisition. Here these energy maintenance strategies served to safeguard future functioning and facilitated ease in present functioning. The finding that MS-F management implicated energy maintenance is consistent with the findings of other MS-F researchers (Blaney & Lowe-Strong, 2009; Flensner et al., 2003; Smith et al., 2015; Stuifbergen & Rogers, 1997). Furthermore, this finding also corresponds to reports that energy maintenance is valuable to fatigue management in conditions such as RA (Feldthusen et al., 2013), IBD (Czuber-Dochan et al., 2013), and MND (Gibbons et al., 2013). Given this consistency, it appears that MS-F sufferers may regard energy maintenance as the route/way by which to manage MS-F. Accordingly, it seems that to manage MS-F, means to implement energy maintenance strategies and tactics.

As highlighted before, energy maintenance involved three energy maintenance strategies. The first energy maintenance strategy (i.e. energy regeneration) was found to be a valuable yet undependable way for managing MS-F. Whilst participants regarded energy regeneration as a useful MS-F management strategy; they deemed it to be ineffectual at managing MS-F on occasion. This finding is consistent with Mills and Young's (2008) finding that sleep was typically incapable of alleviating MS-F. The aforenoted finding suggests that energy regeneration is undependable since it may fail at alleviating/mitigating MS-F. For example, an MS-F sufferer may go to bed tired and wake up either tired or energised. Despite this undependability, participants still regarded energy regeneration as valuable to MS-F management. This finding converges with the findings of other qualitative studies on MS-F (Malcomson et al., 2008; Mills & Young, 2008; Mozo-Dutton et al., 2012; Stuifbergen & Rogers, 1997). As such, energy regeneration may signify a valuable, yet undependable, route by which to manage MS-F.

Besides energy regeneration, energy maintenance also involved energy conservation. Participants perceived energy conservation as a valuable route by which to manage MS-F and safeguard both present and future functioning. This finding is convergent with research reporting that energy conservation is implicated in MS-F management (Johnson et al., 2004; Stuifbergen & Rogers, 1997), and congruent with Smith et al.'s (2015) and Malcomson et al.’s (2008) findings on MS-F management. Thus, the present study affirms research that posits energy conservation to be a MS-F management strategy. The present finding suggests that energy conservation may typify how MS-F sufferers manage MS-F. Accordingly, energy conservation seems to signify a route to effective MS-F management.

Energy acquisition was the last energy maintenance strategy identified in this study. Participants perceived energy acquisition as a route by which to manage MS-F. Here energy acquisition tactics appeared to revitalise participants thereby safeguarding their functioning. The present finding is convergent with Stuifbergen and Rogers’s (1997) theme “recharge efforts” (p. 7), and is congruent with reports that PwMS manage MS-F through stimulant use (Stuifbergen & Rogers, 1997), massaging, stretching (Moriya & Kutsumi, 2010) nutrition, and physical activity (Mills & Young, 2008; Stuifbergen & Rogers, 1997). Collectively, existing literature supports the finding that energy acquisition constitutes a route to MS-F management. Therefore, it appears that energy acquisition may typify MS-F sufferers’ everyday attempts at managing MS-F.

The finding that energy maintenance constituted a route towards MS-F management posits energy maintenance as being important in effective MS-F management. The finding suggests that if

MS-F management is realised through energy maintenance; then more effective MS-F management should signify more effective energy maintenance. This implication suggests that MS-F sufferers' wellbeing could be promoted through psychoeducational interventions which teach effective energy maintenance strategies. Nonetheless, such an intervention would also be subject to the same limitations I highlighted when discussing an intervention centring around preparation.

6.4 The Meaning of Coping with MS-F

In this study, PwMS understood coping with MS-F as an acceptance of the fatigued self and a fatigued life. This understanding involved participants perceiving coping as the: (a) acceptance of MS-F and MS-F's restrictions on life, and (b) an acceptance of MS-F as a FOL. These perceptions comprised in participants' understanding of coping are discussed through the ensuing subsections.

6.4.1 Acceptance of MS-F and MS-F's Restrictions on Life

An acceptance of MS-F and its restrictions on life was perceived as valuable to coping. Here coping appeared attainable by accepting MS-F as an uncontrollable symptom which restricted one's capacity for participating in the world. This finding is consistent with the findings of other MS-F researchers (Flensner et al., 2003; Moriya & Kutsumi, 2010; Newton et al., 2020; Turpin et al., 2017). Given this consistency, it seems that PwMS may regard coping to emanate (in part) from the aforenoted acceptance. Consequently, coping appears to signify the acceptance of MS-F as an uncontrollable symptom which restricts participation in the world.

The present study also identified two nuanced findings which further clarifies how MS-F sufferers may understand coping. The first nuanced finding was that participants found it difficult to accept MS-F and its restrictions on life. This finding suggests that some MS-F sufferers may appraise the aforenoted acceptance as being challenging. The second nuanced finding was that an acceptance of MS-F and its restrictions on life was thought of as a continual process. Here it appeared that acceptance was something one got closer to attaining as opposed to something that could be attained. This finding suggests that coping may be a dynamic and ongoing process within MS-F sufferers' lives. Notably, the finding that an acceptance of MS-F and its restrictions on life is valuable to coping has one important theoretical implication. This finding implies that the closer MS-F sufferers are to fully accepting MS-F and its restrictions on life; the greater their ability to cope with MS-F. Consequently, it seems plausible that interventions which promote the aforenoted acceptance could enhance MS-F sufferers' wellbeing.

6.4.2 Acceptance of MS-F as a Feature of Life

In this study, participants perceived coping to necessitate an acceptance of MS-F as a FOL. This acceptance was appraised as essential to living life despite MS-F. By accepting MS-F as a FOL, participants were able to "push through" MS-F (i.e. enforce functioning) and live life despite MS-F (i.e. fulfil wishes, goals, needs, and responsibilities). The present finding converges with preceding research findings on how PwMS perceive/conceive coping with MS-F (Flensner et al., 2003; Malcomson et al., 2008; Olsson et al., 2008; Smith et al., 2015). Most of these studies also reported concepts similar to that of "pushing through" MS-F as reported in this study (Flensner et al., 2003; Malcomson et al., 2008; Olsson et al., 2008). Given this convergence, it appears that an acceptance of MS-F as a FOL is central to coping with MS-F. Accordingly, to cope with MS-F appears to mean that one remains committed to living life despite MS-F.

The present study identified two nuanced findings that represent caveats in PwMS's ability to enforce functioning. The first nuanced finding was that "pushing through" MS-F was not consistently feasible. This finding suggests that living life despite MS-F may, on occasion, be untenable despite attempts to enforce functioning. The second more nuanced finding was that "pushing through" MS-F was regarded to be an arduous, demanding, and potentially fatiguing endeavour. This finding suggests that whilst PwMS may be able to enforce functioning when fatigued; the act of "pushing through" MS-F is difficult and costs/uses energy. Consequently, it seems implausible that PwMS could continuously enforce functioning without aggravating MS-F. Moreover, it appears that "pushing through" MS-F has the potential to lead to both advantageous and disadvantageous outcomes.

6.5 Theoretical and Practical Implications of the Research Findings

Thus far I have discussed the theoretical and practical implications of specific research findings in this study. As such, I now discuss the overarching theoretical and practical implications of the research findings. Hereby I hope to highlight the broader utility of the research findings.

Collectively speaking, the findings on how PwMS understood MS-F as a FOL provides the reader with insight into what living with MS-F constitutes. By this I mean that the present study's findings offer experiential insights into:

1. What MS-F "feels like", how MS-F works, and how MS-F manifests.
2. How MS-F typically affects daily life and what MS-F implies for PwMS's everyday lives.
3. What MS-F management entails as well as the value and limitations of MS-F management.
4. What coping with MS-F implies and how coping was valued.

These insights are useful since they permit the reader to come to a deeper understanding of what MS-F signifies in the lives of PwMS. For example, the insights gleaned from how participants understood MS-F as a symptomatic experience could nurture a more comprehensive understanding of what MS-F, as a symptom, entails. Likewise, the findings on MS-F's impacts on daily life could foster a more intimate understanding of the difficulties/concerns that typifies life with MS-F. Such deeper understandings of what MS-F as a FOL denotes could be useful to guiding people who work and interact with PwMS (e.g. HCPs, researchers, caregivers, and interventionists). Nonetheless, it is always possible that certain PwMS may understand MS-F in a manner divergent/different from that reported in this study. Consequently, the present research study's findings should be regarded as providing an initial and tentative insight into what MS-F means and signifies. This insight may then be further refined by conversing with MS-F sufferers.

6.6 Strengths Characterising the Present Study

The present study was characterised by three notable strengths. These strengths were philosophical congruence, transparency, and trustworthiness. Each of these strengths are highlighted and clarified in the ensuing subsections.

6.6.1 Philosophical Congruence

In this research study, I was dedicated to the philosophical underpinnings of IPA as far as possible. This dedication extended beyond a commitment to phenomenology, hermeneutics, and ideography during data analysis. These philosophies also informed my research methodology and discussion of the research findings. For instance, my commitment to ideography informed my choice to collect clinical data which could better contextualise participants' MS-F experiences. Likewise, my commitment to phenomenology led me to discuss the research findings in an unambiguous yet suggestive fashion. The enhancement of philosophical congruence was a strength since it ensured that the findings were relayed more in accordance with IPA's theoretical ability and limitations.

6.6.2 Transparency

A strength of the present study was that I was committed to transparency. This commitment is exemplified through in-depth descriptions of my research paradigm and research methodology. With respect to my research paradigm, this involved making explicit the worldview I espoused in this research study. Additionally, I aspired to be transparent in my research methodology by providing detailed accounts of my research process. This included providing comprehensive accounts of: (a) the sampling strategy and procedure, (b) the data collection methods and process, (c) transcription, (d) the data analysis process, as well as (e) reflexivity and bracketing. Enhanced transparency represented a strength for two reasons. Firstly, greater transparency permits the reader to critically evaluate this study with relative ease. Moreover, by being transparent in what data analysis entailed I provide an analytic guide which future IPA researchers may duplicate.

6.6.3 Trustworthiness

I was committed to enhancing the trustworthiness of the present study's research findings. To do this, I employed various strategies to ensure the credibility, transferability, dependability, and confirmability of the findings (see section 4.7). My commitment to trustworthiness was a strength since it substantiates the veracity and integrity of the research findings.

6.7 Limitations Characterising the Present Study

The present study was characterised by four notable limitations. These limitations were: (a) a lack of a heterogeneous sample, (b) an inability to recruit a "pure" MS-F sample, (c) a non-generalisability of findings, and (d) the analyst as an analytic tool. Each of these limitations are discussed in the ensuing subsections.

6.7.1 Lack of a Heterogenous Sample

The present study explored MS-F in a relatively homogenous sample. Whilst sample homogeneity constitutes a strength by enhancing trustworthiness (Smith et al., 2009/2012d); it also represents a limitation since it restricts how relevant findings are to those unrepresented in the sample. A major limitation of the present study was the lack of ethnic diversity and adequate socio-economic representation. This lack of representation limits the utility of the research findings within the broader SA context.

The present study lacked an ethnically diverse sample and consisted exclusively of white participants. Whilst I aimed to recruit an ethnically diverse sample; regrettably this did not materialise. Of the 30 prospective participants who contacted me, 28 where white with only 2 self-identifying as persons of colour. Both individuals broke contact with me prior to participating in an interview. Seeing as I had been sampling for a protracted period (4 months), and recruitment could not continue ad infinitum, I resolved to discontinue recruitment and make do with my existing data sets. The exploration of the lived experiences of MS-F in an all-white sample would have excluded perceptions and understandings of MS-F routed in, or informed by, other ethnic groups' cultural values, norms, traditions, and belief systems. Given this, the findings of the present study may not encompass all understandings and perceptions of MS-F which exist in the WC. This seems likely given the ethnically diverse and multi-cultural society that South Africa and its provinces represent. Moreover, it is also unknown to what extent the findings may be relevant/applicable to people of colour. Thus, any transferability of the research findings to non-white individuals should be treated with adequate care and scrutiny. A further limitation of the present study was the lack of participants from a low socioeconomic status. The sample consisted almost exclusively of individuals from a middle-income socioeconomic status (*n* = 5). As such, the findings of this study failed to elucidate understandings and perceptions of MS-F routed in, or informed by, a lower socioeconomic status or poverty. Consequently, the findings should not be seen as reflective of how MS-F will be understood by PwMS in a lower socioeconomic setting.

6.7.2 Inability to Recruit a "Pure" MS-F Sample

Whilst I recruited a relevant sample of participants, I did not recruit a "pure" MS-F sample. By this I mean that I did not exclude participants who experienced fatigue as part of comorbid conditions (i.e. conditions besides MS). Much rather, the present sample included participants who suffered from hypertension, high-cholesterol, sleep apnea and Raynaud's disease. Furthermore, I did not exclude participants who may have experienced fatigue as an indirect consequence of MS (i.e. secondary fatigue). That is, those participants who experienced fatigue because of a condition which emanated, or possibly emanated, from MS. In respect to the sample recruited in the present study, this included participants who suffered from clinical depression, heat-sensitivity, pain, sleep disruptions and received psychopharmacological treatment. Whilst an ideal sample would have consisted out of participants not presenting with the aforenoted conditions, I resolved not to exclude such participants over sample size concerns. Given the vast amount of non-MS and indirect MS-related sources of fatigue I would have had to exclude, I would not have been able to recruit an adequately sized sample. Nevertheless, I attempted to accommodate and overcome confounding of the findings by:

1. Excluding all data segments which were explicitly unrelated to MS or potentially unrelated to MS.
2. Reporting on participants' co-morbidities which may have contributed to MS-F and confounded the findings.

Furthermore, it should be noted that most participants were able to qualitatively distinguish between different "types" of fatigue. Participants could distinguish MS-F from overexertion, general fatigue, and fatigue in depression. Therefore, participants' in-depth understanding of MS-F mitigated (to some extent) the threat that non-MS sources of fatigue posed to trustworthiness.

6.7.3 Non-generalisability of Findings.

The findings of the present study are not generalisable across groups/populations of MS-F sufferers. This incapability persists irrespective of the degree to which said group/population corresponds to the demographic and clinical features of the present study's sample. The findings of the present study are intended to provide the reader with an understanding of how some PwMS understand MS-F as a FOL. In this respect, the findings provide insight into those understandings and perceptions which may underly some PwMS's experiences of MS-F. Emphasis here is placed on "some" since it is possible that other understandings and perceptions of MS-F exist which were not espoused by the participants in this study. Concurrently, it is also possible that some PwMS may not ascribe to the perceptions and understandings identified in this study. Thus, whilst the findings of the present study may be relevant and transferable to certain cases of MS-F; these findings may be less relevant and transferable to other cases of MS-F. Given this, care should be taken to use the present findings in a responsible and considered manner. To this effect, I advise that any transference of findings should be treated as preliminary until either affirmed or disaffirmed. The research findings provide an initial understanding which should be refined into more individualised understandings through person-centred dialogue or open-ended research methodologies.

6.7.4 The Analyst as an Analytic tool

The present study accessed participants' meanings and sense-making through a phenomenological approach to interpretation. In doing this, I attempted to be phenomenological in my interpretations as far as possible. Despite this commitment, I acknowledge that it is impossible to be fully and consistently phenomenological in interpretation. Whilst I continuously reflected on, and attempted to bracket off, my personal features and precognitions during data analysis; it is likely that I was not consistently successful. It is probable that I, on occasion, may have failed to bracket off personal features or precognitions (whether I had insight into them or not) during my interpretation of participants' lived experiences. Whilst the cyclic iterations of interpretation I engaged in served to diminish the potential for analyst bias, it by no means negates it. I, as the analyst, constituted the analytic tool. Thus, despite attempts at being phenomenological, I am inherent to and inseparable from the findings. Consequently, the findings represented the outcomes of my interpretation of how participants interpret their lived experiences of MS-F (i.e. my understanding of their understanding). Something which would never fully reflect how PwMS themselves understand MS-F as a FOL.

6.8 Recommendations for Future Studies

In familiarising myself with the broader literature on MS-F, I have identified a few areas where future research would be invaluable. Firstly, research aimed at developing a more comprehensive definition for MS-F would be invaluable to the academic world. The lack of a robust and agreed upon definition for MS-F may compromise the integrity of inquiries into MS-F. Moreover, the lack of descriptive richness in most contemporary definitions of MS-F makes it difficult to distinguish MS-F from other "types" of fatigue. As such, it is recommended that future research should seek to address the issues characterising contemporary definitions of MS-F. Furthermore, research seeking to explore how PwMS understand MS-F within a non-white sample and/or in a low socioeconomic setting would also be valuable. The present study failed to explore the lived experiences of MS-F amongst an ethnically and socioeconomically diverse sample. Given this failure, it is recommended that future research be directed at exploring the lived experiences of MS-F amongst PwMS not represented in this study. Here such research could not only identify other alternative perceptions/understandings of MS-F; but could also inform the development of more culturally sensitive and contextually relevant interventions for MS-F sufferers in SA.

A third matter which should be further researched is how PwMS's understandings of MS-F compare with HCPs understandings of MS-F. I recommend this because participants described how healthy people (i.e. those not suffering from chronic fatigue) frequently misunderstood MS-F.

Research into whether this misunderstanding exists in the health care sector could offer insight into the quality of care received by MS-F sufferers in SA. A final suggestion for future research would be to quantitatively determine the degree/extent to which MS-F sufferers ascribe to the perceptions identified in this study. Such research would be valuable since it could quantify the transferability of the present study's research findings and determine the salience of the present study's findings relative to the broader literature on MS-F.

6.9 Conclusion

In this chapter, I discussed the findings on how PwMS in the WC understood MS-F as a FOL. Furthermore, I also underscored the theoretical and practical implications of the research findings. This included the specific and broader implications of the research findings. Despite being characterised by limitations, the present study was committed to philosophical coherence, transparency, and enhanced trustworthiness. In this manner, the present study contributed to existing literature on MS-F as well as the development of IPA as a methodology. Nonetheless, despite this study's contribution to literature on MS-F, gaps in existing knowledge on MS-F persist.

As I illustrated in this chapter, MS-F implied a pronounced energetic deficiency which manifested through physical and mental phenomena. This subjective experience appeared to be an ever-present FOL that varied in its presence and severity. Living with MS-F appeared to mean that everyday life was typified by a restricted capacity to participate in the world, which encompassed a restricted functional capacity as well as losses in both independence and spontaneity. Here this restricted capacity to participate in the world elicited undesirable emotions and negative appraisals of life. Furthermore, it appeared that MS-F management was preparatory in nature with preparation representing the intent/goal of MS-F management. This preparation implied energy maintenance with energy maintenance itself representing the way by which to manage MS-F. Here energy maintenance involved energy regeneration, energy conservation, and energy acquisition as MS-F management strategies. Moreover, coping seemed to denote an acceptance of the fatigued self and a fatigued life. To cope with MS-F meant to accept MS-F's uncontrollable nature, MS-F's restrictions to life, and MS-F as a FOL. However, this acceptance appeared to be a challenging and ongoing process. Overall, the present study found MS-F to be a salient and meaning laden phenomenon. This was evident in that MS-F signified and implied several prominent things for MS-F sufferers and their lives. Taken together, the present study brought MS-F sufferers' concerns of MS-F firmly into focus.

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Appendix A: Flyer Advertisement

DO YOU HAVE MS AND EXPERIENCE FATIGUE?

If so, please consider participating in a study looking at what it is like for people with MS to live with fatigue

I am looking for people:

- Older than 18
- Living in the Western Cape
- Experiencing mild or severe fatigue
- That do not have a current relapse, or had a relapse in the last three months.
- That have been diagnosed with MS for at least a year

If this sounds like you, and you are interested in participating, contact me to schedule / complete a 5 minute screening questionnaire which will assess your eligibility.

PRIMARY INVESTIGATOR: Nick van Niekerk

Background: I am a masters student affliated with the Psychology Department of Stellenbosch University. I am currently pursuing my MA (Psychology) through this research project which is supervised by Dr. Bronwyne Coetzee and co-supervised by Dr. Chrisma Pretorius.

Email: Nickvn@outlook.com or 17729254@sun.ac.za
Cell / Whatsapp: 072 398 2130

Appendix B: Screening Questionnaire

I am going to ask you a number of questions to determine your eligibility for participation in this study. The questions are focused on demographics, information about your MS diagnosis, your experience of fatigue, and other potential states that may contribute to your fatigue.

1. How old are you (in years)? ______________________
2. Do you live in the Western Cape?
   - ○ Yes
   - ○ No
3. Has your MS diagnosis been medically confirmed?
   - ○ Yes
   - ○ No
4. How long ago (in years) were you medically diagnosed with MS? ______________________
5. Are you currently having an MS related relapse?
   - ○ Yes
   - ○ No
6. Have you had an MS related relapse within the past three months?
   - ○ Yes
   - ○ No
7. Do you experience fatigue as one of your symptoms of MS?
   - ○ Yes
     - i. If you had to select one of the following, which would best describe the intensity of your fatigue?
       - ○ Mild
       - ○ Moderate
       - ○ Severe
   - ○ No

[To be completed if the prospective participant meets the inclusion criteria] *I have looked over your responses to the questions and would like to formally invite you to participate in this study. If you are willing to participate in the individual telephonic interviews about your experiences of living with fatigue, and a subsequent questionnaire, I'd like to note down your contact details and schedule a date and time for me to call you. Alternatively, should you feel uncomfortable with a telephonic interview, we can conduct either a Skype interview or an at home face-to-face interview if you live within a 50 km drive from Stellenbosch. I will also be emailing you a copy of an informed consent form containing more information about the study for you to read through and sign.*

Assigned code identifier:			
Interview Platform:	Telephonic	Skype	Face-to-Face
Date of interview:			
Time of interview:			
Cell phone number of participant:			
Email address of participant:			
* Address: *NOTE: Only to be asked in instances where the participant indicates a preference for face-to-face interviews AND lives within a 50 km drive from Stellenbosch*			

Appendix C: Biographical Questionnaire

I am going to ask you a number of questions to collect some information relevant to the current study. These questions will collect some demographic data, information about your MS diagnosis, and other potential conditions that may contribute to your fatigue. I will read out each question along with its response options if the question is not open-ended and write down your answer.

1. At what age did you first start experiencing MS-related symptoms?

   ____

2. What subtype of MS do you have?
   - ○ Relapsing-remitting multiple sclerosis (RRMS)
   - ○ Primary progressive multiple sclerosis (PPMS)
   - ○ Secondary progressive multiple sclerosis (SPMS)
   - ○ Progressive relapsing multiple sclerosis (PRMS)
   - ○ I don’t know
3. Have you ever been diagnosed with any mental disorder(s)?
   - ○ Yes
     - ➢ Please specify: ____
   - ○ No
   - ○ I don’t know
4. Have you ever been diagnosed with any neurological condition(s) besides MS?
   - ○ Yes
     - ➢ Please specify: ____
   - ○ No
   - ○ I don’t know

5. Do you currently suffer from any other major health condition(s) (e.g., cardiovascular illnesses)?
    - ○ Yes
        - ➢ Please specify: ______________________________________
    - ○ No
    - ○ I don’t know
6. With which gender do you identify?
    - ○ Male
    - ○ Female
    - ○ Other:
        - ➢ Please specify: ______________________________________
7. What racial group do you identify with?
    - ○ African
    - ○ Coloured
    - ○ White
    - ○ Indian
    - ○ Other:
        - ➢ Please specify: ______________________________________

8. What is your home language?

   - ○ Afrikaans
   - ○ English
   - ○ Ndebele
   - ○ Northern Sotho
   - ○ Sotho
   - ○ SiSwati
   - ○ Tsonga
   - ○ Tswana
   - ○ Venda
   - ○ Xhosa
   - ○ Zulu
   - ○ Other:
     - ➢ Please specify: ____

9. Does anyone live with you in your house/apartment?

   - ○ No
   - ○ Yes:
     - ➢ Please describe: ____

10. What is your relationship status?

    - ○ Single
    - ○ In a committed relationship
    - ○ Married
    - ○ Separated
    - ○ Widowed
    - ○ Other:
      - ➢ Please specify: ____

11. What is the highest level of education that you have attained?

    ○ I've had no formal education

    ○ I completed primary school

    ○ I attended high school but did not matriculate

    ○ I matriculated

    ○ I attended a tertiary institution (e.g., a University, College, Technicon) but did not graduate

    ○ I graduated from a tertiary institution (e.g., a University, College, Technicon)

12. How would you describe your socio-economic status?

    ○ Low income

    ○ Low-middle income

    ○ Middle income

    ○ High-middle income

    ○ High income

13. What is your current employment status?

    ○ Employed full time

    ○ Employed part time

    ○ Student

    ○ Unemployed

    ○ Homemaker

    ○ Retired

14. Did your employment status or profession change as a result of MS disease progression?

    ○ Yes

    ○ No

Only ask this question if the participant selected yes as a response to Question 14:

15. What was your employment status prior to the marked progression of MS?

○ Employed full time

○ Employed part time

○ Student

○ Unemployed

○ Homemaker

○ Retired

Appendix D: The Patient-determined Disease Steps

The Patient Determined Disease Steps (PDDS) and Performance Scales (PS) are self-assessment scales of multiple sclerosis disease status collected in the North American Research Consortium on Multiple Sclerosis (NARCOMS) Registry at enrolment and semi-annual follow up surveys. The PDDS/PS are not copyrighted instruments, however the authors of PDDS/PS request that if you use the PDDS/PS as given below or from www.NARCOMS.org/PDDS that NARCOMS be acknowledged when using or publishing work with these questions and that the following references be cited:

PDDS & Performance Scales:

Hohol MJ, Orav EJ, Weiner HL. Disease Steps in multiple sclerosis: A simple approach to evaluate disease progression. Neurology 1995; 45: 251–55.

Hohol MJ, Orav EJ, Weiner HL. Disease Steps in multiple sclerosis: a longitudinal study comparing disease steps and EDSS to evaluate disease progression. Multiple Sclerosis 1999; 5: 349–54.

Marrie RA and Goldman M. Validity of performance scales for disability assessment in multiple sclerosis. Multiple Sclerosis 2007; 13: 1176-1182.

Additional Reference for the Performance Scales:

Schwartz CE, Vollmer T and Lee H. Reliability and validity of two self-report measures of impairment and disability for MS. North American Research Consortium on Multiple Sclerosis Outcomes Study Group. Neurology. 1999; 52: 63-70.

Acknowledgement for use:

The PDDS and/or PS are provided for use by the NARCOMS Registry: www.narcoms.org/pdds. NARCOMS is supported in part by the Consortium of Multiple Sclerosis Centres (CMSC) and the CMSC Foundation.

We hope the PDDS and PS are useful in your studies, and appreciate the above citations and reference

Robert J. Fox

Robert Fox, MD
Managing Director
NARCOMS

Ruth Ann Marrie

Ruth Ann Marrie, MD, PhD
Scientific Director
NARCOMS

PDDS: Patient-determined Disease Steps

Please read the choices listed below and choose the one that best describes your own situation. **This scale focuses mainly on how well you walk**. You might not find a description that reflects your condition exactly, but please mark the **one** category that describes your situation the closest.

☐ 0 **Normal:** I may have some mild symptoms, mostly sensory due to MS but they do not limit my activity. If I do have an attack, I return to normal when the attack has passed.

☐ 1 **Mild Disability**: I have some noticeable symptoms from my MS but they are minor and have only a small effect on my lifestyle.

☐ 2 **Moderate Disability:** I don't have any limitations in my walking ability. However, I do have significant problems due to MS that limit daily activities in other ways.

☐ 3 **Gait Disability:** MS does interfere with my activities, especially my walking. I can work a full day, but athletic or physically demanding activities are more difficult than they used to be. I usually don't need a cane or other assistance to walk, but I might need some assistance during an attack.

☐ 4 **Early Cane**: I use a cane or a single crutch or some other form of support (such as touching a wall or leaning on someone's arm) for walking all the time or part of the time, especially when walking outside. I think I can walk 25 feet (approximately 7.5 meters) in 20 seconds without a cane or crutch. I always need some assistance (cane or crutch) if I want to walk as far as 3 blocks.

☐ 5 **Late Cane:** To be able to walk 25 feet (approximately 7.5 meters), I have to have a cane, crutch or someone to hold onto. I can get around the house or other buildings by holding onto furniture or touching the walls for support. I may use a scooter or wheelchair if I want to go greater distances.

☐ 6 **Bilateral Support:** To be able to walk as far as 25 feet (approximately 7.5 meters) I must have 2 canes or crutches or a walker. I may use a scooter or wheelchair for longer distances.

☐ 7 **Wheelchair / Scooter:** My main form of mobility is a wheelchair. I may be able to stand and/or take one or two steps, but I can't walk 25 feet (approximately 7.5 meters), even with crutches or a walker.

☐ 8 **Bedridden**: Unable to sit in a wheelchair for more than one hour

Appendix E: The Chalder Fatigue Scale

We would like to know more about any problems you have had with feeling tired, weak or lacking in energy in the last month. Please answer ALL the questions by ticking the answer which applies to you most closely. If you have been feeling tired for a long while, then compare yourself to how you felt when you were last well. Please tick only one box per line.

	Less than usual	***No more than usual***	***More than usual***	***Much more than usual***
1. Do you have problems with tiredness?				
2. Do you need to rest more?				
3. Do you feel sleepy or drowsy?				
4. Do you have problems starting things?				
5. Do you lack energy?				
6. Do you have less strength in your muscles?				
7. Do you feel weak?				
8. Do you have difficulties concentrating?				
9. Do you make slips of the tongue when speaking?				
10. Do you find it more difficult to find the right word?				
	Better than usual	***No worse than usual***	***Worse than usual***	***Much worse than usual***
11. How is your memory?				

This scale can be scored "bimodally" with columns representing 0, 0, 1 & 1 and a range from 0 to 11 with a total of 4 or more qualifying for "caseness". Alternatively it can be scored in "Likert" style 0, 1, 2 & 3 with a range from 0 to 33. Mean "bimodal" score for CFS sufferers was 9.14 (SD 2.73) and for a community sample 3.27 (SD 3.21). Mean "Likert" score was 24.4 (SD 5.8) and 14.2 (SD 4.6).

Total Score (0-33) =

Cella, M. and T. Chalder (2010). *"Measuring fatigue in clinical and community settings."* J Psychosom Res 69(1): 17-22. This study involved 361 CFS sufferers and 1615 individuals from the community. Average age was in the 30's. Fatigue levels were similar for males and females. A score of 29 discriminated between CFS sufferers and the community sample in 96% of cases and a score in the 30's discriminated in 100% of cases. The CFS sufferers also scored a mean of 26.99 on the Work & Social Adjustment Scale (W&SAS) with a SD of 8.6 (i.e. about 70% scoring between 18.4 and 35.6).

Appendix F: Semi-Structured Interview Guide

Pre-interview Opening Statements

Before we start, I'd just like to say thank you for your willingness to participate in this study. I'm looking forward to seeing what we will discover in this interview. This interview will take around 30 minutes to an hour. There should be more than enough time to answer the questions, so we don't need to rush. Should you at any time become distressed in that you have any uncomfortable feelings or emotions please let me know and we'll take it from there. I would just like to restate the purpose of this research study. With this interview, I am trying to understand the fatigue you experience from your perspective (Make sure they understand this).

Introductory Questions

1. Can you walk me through a typical day in your life? (i.e. from when you get up in the morning, until you go to sleep at night)
    a. Probe: Can you tell me a story about/give me an example of a situation in which you were fatigued?

I am using this word "fatigue" and maybe fatigue is not the word you use. So, I wanted to ask…

2. How would you define fatigue?
    a. Probe: How would you explain your fatigue to others (to your friends/ family)?

Questions about MS-F's Symptomatic Experience

3. Can you reflect on differences in how you experience fatigue now compared to before you started having MS symptoms?
4. How does fatigue impact you physically (i.e. how your body works)?
    a. Probe: Do you have any sensations in your body when you are fatigued?

We've spoken about the impact your fatigue has on your body, but I'm wondering about your everyday thinking or the ways in which (if any) fatigue impacts on your thinking?

5. How does fatigue impact your thinking or thoughts?

Questions about MS-F's Impacts on Daily Life

6. Can you tell me a bit about what it is like for you to live with fatigue?
    a. Follow-up questioning:
        i. How has fatigue impacted your common daily activities, tasks, and responsibilities? (e.g. household tasks such as cleaning/cooking)
        ii. What lifestyle changes have you had to make because of fatigue?
        iii. In what way or ways, if any, has fatigue affected your social life?
            - Probe: How well do you think your friends understand your experiences of fatigue?
        iv. Has fatigue affected your family life in any way?
            - Probe: How well do you think your family understands your experiences of fatigue?
        v. In what way or ways, if any, has fatigue affected your job and career?
            - Probe: How well do you think your employer and colleagues understand your experiences of fatigue?

Questions about Coping with and Managing MS-F

You've told me about how you experience fatigue in your body and mind, and about how fatigue has impacted your everyday life. I'm just thinking about and wondering how, given all of this, you have coped with, and managed your fatigue?

7. How have you coped with fatigue? (i.e. throughout your life)
    a. Probe: How do you handle your fatigue?
8. What specifically have you done to manage the fatigue you experience? (i.e. on the days you are fatigued)
    b. Probe:
        i. What things have you done to manage the impact fatigue has on your daily life?
        ii. Do your family members or others help you to manage the impact that fatigue has had on your life, and if so, how?

Post-interview closing statements.

So, this concludes the interview part of the research. Yet again, thank you for participating in this research study. I wanted to hear whether it would be alright if I contact you about this interview should I need some clarity about something you mentioned? Alright, I am going to turn off the audio recorder now and we can then move on to the questionnaires.

Appendix G: Follow Up Interview Guide

(Participant's name) I would like to say thank you for being willing to participate in this follow up interview. I am going to turn on the audio recorder now. When we last spoke you indicated that you have been diagnosed with depression. Because of this I would like to ask you a few more questions if that is alright with you?

1. Do you experience fatigue as a part of depression?
   a. Yes
   b. No
   c. I don't know

If the participant answers "no" skip to the last paragraph.

2. How does your experience of fatigue in MS compare to your experience of fatigue in depression?
   a. Probe for features that are shared by MS-F and depression related fatigue.
   b. Probe for features that differ between MS-F and depression related fatigue.

3. When where you diagnosed with depression?
   a. Probe for whether depression was diagnosed or self-diagnosed.
   b. Probe for how long participants have experienced depressive symptoms.
   c. Probe for when depressive symptoms developed relative to MS symptoms.

(Participant's name), thank you for answering my questions. Your answers have helped me come to a better understanding of what we spoke about during our previous interview. I am going to turn the audio-recorder off now.

Appendix H: IPA oriented Transcription Convention

Table H1

Transcription Convention used during Transcription

Linguistic Feature	Symbol	Description
Falling intonation	.	Falling intonation followed by an unmistakable pause was indicated by a punctuation mark.
Rising intonation	?/!	Rising intonation followed by an unmistakable pause was indicated by a question mark. These symbols were also used following expletive and questioning statements.
Continuing intonation	,	Used to indicate speech demonstrating slight rises or falls in contour followed by a pause shorter than "." or "?".
Short pause	(*)	Definitions for what represents a short, long, and very long pause were subjective in nature.
Long pause	(**)	
Very long pause	(***)	
Overlapping Speech	[text]	Square brackets indicated the point at which speech overlap starts ([ ) and ends ( ]). They were positioned in alignment of where the overlap occurs between interviewer and participant.
Discontinued speech	–	Cut off of speech is indicated by a dash between words (e.g., this is – No. I don't think).
	-	Cut off and repeating sounds within words were indicated by hyphens (e.g., bu-u-).
	…	This designates words trailing off
Laughter	heh heh heh	Symbolises verbalised laughter between words, and utterances
	^^ text ^^	Words spoken with as the speaker laughed was indicated by being transcribed with two carets on either side of the word.
Utterances	e.g., Um/Ah	Utterances were transcribed verbatim as they were sounded out.
Noticeable breathing	hhh	Represents a pronounced inhaling sigh with more h's signifying greater inhalation.
	HHH	Represents a pronounced exhaling sigh with more H's signifying greater exhalation.
Dubious speech	(text)	Parenthesised text indicated words and utterances that was hesitantly transcribed over difficulties deciphering speech.
Inaudible content	( )	Recorded content that was inaudible to the transcriptionist was indicated by parentheses. Here the timestamp of inaudible content was provided within the parentheses.
Additional linguistic phenomena	((text))	Those additional lingual features noticeable within audio recordings such as, for example, sighs, snorts, coughs, etc.

Appendix I: Data Analysis Strategy

The data analysis procedure in the present study was routed in an overarching research strategy. In accordance with Smith et al. (2009/2012c), the following strategies were implicit within the present study's data analysis procedure:

1. Conducting a close line-by-line analysis of each individual participant's descriptions, experiences, and perceptions of MS-F as a FOL.
2. Identifying semantic patterns (i.e. patterns in meaning and sense-making) within participants' accounts of living with MS-F. This includes the identification of similar, dissimilar, convergent, and divergent perceptions and understandings. Here semantic patterns were first identified within individual transcripts before being identified across all transcripts.
3. Engaging with narrative data in a reflective and iterative manner so that I could more accurately interpret what living with MS-F signified within participants' lives.
4. Attempting to visually illustrate how perceptions and notions of MS-F were linked in participants' sense-making of MS-F as a FOL.
5. Organising data analysis so that interpretations could be traced throughout the entire data analysis procedure.
6. Relying on my supervisors to audit the data analysis approach. Here this involved my supervisors qualitatively assessing the coherence and plausibility of my interpretations.
7. Engaging in an iterative and cyclical process of self-reflection so that I could better identify and attempt to bracket off my taken-for-granted sense-making processes.

Appendix J: Template of IPA Analysis Table

Figure J1.

Template of IPA Analysis Table used during Data Analysis

Themes	Original Transcript	Exploratory Comments
Themes were identified within this column.	Participants’ transcribed accounts of living with MS-F was copied and pasted into this column.	Exploratory commenting was conducted within this column.

Figure J1. Template illustrating the IPA analysis table used during the analysis of participants’ lived experiences of MS-F. This template was duplicated from Smith et al. (2009/2012c) who highlighted this table as well suited to conducting IPA analyses.

Appendix K: Illustrative Extract of Data Analysis

Figure K1.

Illustrative Extract of the Data Analysis Process

Themes	**Original Transcript**	**Exploratory Comments**
	Interviewer: I-I was wondering how would you define fatigue?	
MS-F as a pronounced physical powerlessness	**Participant:** Well, if I had to describe it, it would be… sitting there and realising that if the house started burning, you actually would burn to death because you're too tired to get up, that's fatigue. Whereas if you're tired, you'll still get up, if you're fatigued you just, you physically cannot do it.	MS-F involves a physical immobilisation. Does one then lack the power/energy for volitional body movements? Physical helplessness? *"actually would burn to death" posits MS-F as a severe phenomenon/symptom.* MS-F as less severe than tiredness. MS-F differs from general fatigue through a loss of bodily power. MS-F involves a loss of physical power Here MS-F serves to inhibit/subvert physical functioning. *"physically cannot" emphasises the severity of MS-F's inhibitory effect.*
MS-F management involves preparation	You know, you have to rest after taking a shower ^^or ^^ heh heh heh or before you can	Managing MS-F involves resting for imminent future functioning. Does living with MS-F imply self-preparation as a common aspect of life?
MS-F as subverting functioning	blow dry your hair because you can't do both at once because then you're too tired to get dressed.	MS-F subverts successive task/activity performance unfeasible. Functional continuance itself appears unfeasible. *The laugh seems to allude to discontent and/or annoyance.* Notably, MS-F renders even those relatively "mundane" activities as unfeasible.

Figure K1. Analysed data extract which illustrates what data analysis looked like. Distinct exploratory comments were distinguished through stylistic features. Normal text represents descriptive comments, italicised text represents linguistic comments, and underlined text represents conceptual comments. Note that themes were identified in relation to all exploratory comments linked to a specific data segment as well as other relevant data segments throughout a transcript.

Appendix L: Reflecting on IPA as an Analytic Approach

Within this Appendix, I reflect on what it was like for me to conduct this IPA research study. Through this reflection I convey what it felt like to conduct and IPA analysis and to write up my research findings. Please note that the ensuing discussion reflects my own subjective experience and informed opinion on IPA as an analytic approach.

How it Feels to Conduct an IPA Analysis

Conducting an IPA analysis is quite the undertaking. I am not saying this to dissuade or discourage researchers from conducting IPA analyses. Much rather, I want to draw attention to how time consuming and mentally intensive IPA can be. Prior to conducting my IPA analysis, I remember reading how doing an IPA analysis was one part “doing things” and two parts “thinking about things”. I remember reading this and thinking: “Surely you must be mistaken or exaggerating?” Having conducted an IPA analysis myself, I can affirm this assertion.

During my analysis, I frequently found myself immersed within the same data segment for prolonged periods of time. Additionally, IPA’s reflexive, cyclical, and iterative approach to interpretation (whilst essential for maturing my interpretations) was itself very time consuming. I found this time-consuming nature of IPA to be quite overwhelming and frustrating. That said, I do believe that sufficient time is needed to conduct a rigorous and trustworthy IPA analysis. There is no “rushing” an in-depth and rigorous IPA study. I think that such an attempt would most likely result in overly descriptive research findings. Conducting an IPA study is like baking a soufflé. Take it out too early, and the IPA falls flat leaving you with findings more akin to a thematic analysis; leave it in too long, and you scorch your IPA by ending up with overly abstracted findings. Striking an adequate balance between description and conceptual abstraction in an IPA study is paramount. Here this balancing act requires ample consideration, and hence, requires time. If I were to compare IPA to wine, I would say that IPA tastes like a full-bodied glass of red wine on a cold winter’s evening. Like red wine, IPA research findings should be deep, dense, and heavy with subtle hues and nuanced undertones. To achieve these characteristics, your IPA results (i.e. interpretations) need time to sufficiently mature through the hermeneutic circle.

In addition to being time consuming, I found IPA to be a very mentally intensive data analysis process. Thinking in IPA frequently involves metacognitive processes in which:

1. You think about your participants and how they think.
2. You think about yourself and how you think.
3. You think about how you think about your interpretations.

With reference to the above listed points, it is the third metacognitive process that I found to be particularly mentally taxing and demanding. This metacognitive process revolves around (i.e, fosters insight into) how your thinking affects the interpretational process. Developing insight into said cognitive process is attainable, but often difficult, and sometimes feels like you just “hit a brick wall”. Moreover, whilst you can develop substantial insight into your personhood and thinking, you will never have complete insight into your interpretative processes. Nonetheless, reflecting on your thinking during interpretations is essential. Some tactics that worked well for me here was to:

1. Audio record me speaking about my thinking and then relistening to the audio recording. This helped me to externalise my thoughts so that I could better reflect on my thinking.
2. If my thinking “hit a brick wall”, I would take a break from analysing the data. By suspending my analysis in this way, I could better “see the wood for the trees”.

Conducting an IPA analysis can seem quite overwhelming. It requires substantial time, mental space, and commitment from the researcher. This point is particularly relevant to the commenting phase in IPA when the data you have expands dramatically (see subsection 4.4.3.2). That said, an IPA analysis does become less demanding and difficult following this commenting process (provided you made rigorous comments). Moreover, as you become more familiar with yourself, your data, and IPA itself, the data analysis process becomes easier. Being relentless and persistent in your adherence to IPA’s theoretical foundations is the key to achieving your goal with

IPA. Accordingly, to any fledgling IPA researcher reading this: “You will get there. There is light at the end of this tunnel. Just follow IPA’s philosophical underpinnings.”

How it Feels to Write up the Findings of an IPA Analysis

Writing up IPA research results and findings is no trivial or simple matter. I cannot fathom a guess at how many times I rewrote and reformulated how I presented my results and research findings. Here I am not speaking about rewriting and reformulating themes and interpretations to reflect meanings more accurately (i.e. refinement during data analysis). Much rather, I am speaking about rewriting and reformulating how I presented my findings to convey my understanding (i.e. my interpretation of meaning) to the reader. The act of literarily conveying meanings to the reader was, on occasion, quite a difficult act. I mostly experienced this difficulty when trying to communicate more conceptually abstracted perceptions and understandings. I found it more difficult to convey such meanings since language did not always readily lend itself to conveying them. Rather, I found language to be a barrier that could hinder me from conveying more abstract meanings as I understood them (i.e. language frustrated the act of me conveying my understandings as I intended to convey them). If I was to describe what this difficulty “felt” like I would say that: “it feels like you are trying to relay something so fundamentally basic that words themselves become inadequate”. To convey to you what I mean by this, try answering the following question: “How would you describe what yellow looks like to someone that has never seen colour?” Think about how you feel when thinking about and trying to answer this question. Think about how you feel when you are trying to find the words to convey something so basic and fundamental in most people’s lives as colour. That is what the difficulty with language felt like when language hindered me in conveying meaning as I intended. Nonetheless, since I cannot transfer my understanding of what living with MS-F meant directly into the readers’ consciousness, language must suffice despite its shortcomings. Moreover, I have always been an avid reader, and hence, I have developed quite a robust vocabulary over time. When conducting this study, I found my large vocabulary to be an invaluable asset which assisted me in conveying meanings as I intended to convey them.

Appendix M: Ethical Approval

Approved with Stipulations

New Application

15/10/2018

Project ID: 7662

HREC Reference #: S18/07/151

Title: Exploring Fatigue amongst Individuals Living with Multiple Sclerosis: A South African Perspective

Dear Mr Nicolaas van Niekerk

The **New Application** received on 03/10/2018 13:16 was reviewed by members of the **Health Research Ethics Committee** via Minimal Risk Review procedures on 15/10/2018 and was approved with stipulations.

Please note the following information about your approved research protocol**:Protocol**

Approval Period: 15-Oct-2018 – 14-Oct-2019.

The stipulations of your ethics approval are as follows:

Provisions should be made for participants who are visually impaired and they should not be excluded from the study.

Please remember to use your project ID 7662 and ethics reference number S18/07/151 on any documents or correspondence with the HREC concerning your research protocol.

Translation of the consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Please note that this decision will be ratified at the next HREC full committee meeting. HREC reserves the right to suspend approval and to request changes or clarifications from applicants. The coordinator will notify the applicant (and if applicable, the supervisor) of the changes or suspension within 1 day of receiving the notice of suspension from HREC. HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note you can submit your progress report through the online ethics application process, available at: https://apply.ethics.sun.ac.za and the application should be submitted to the Committee before the year has expired. Please see Forms and Instructions on our HREC website for guidance on how to submit a progress report.

The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomlyfor an external audit.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: https://www.westerncape.gov.za/general-publication/health-research-approval-process. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: Forms and Instructions on our HREC website (www.sun.ac.za/healthresearchethics)

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Mr F Weber
Health Research Ethics Committee 1 (HREC1)

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)•REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1)•IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

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Approval Letter
Progress Report

23/10/2019

Project ID: 7662

Ethics Reference No: S18/07/151

Project Title: Exploring Fatigue amongst Individuals Living with Multiple Sclerosis: A South African Perspective

Dear Mr Nicolaas van Niekerk

We refer to your request for an extension/annual renewal of ethics approval received 10/10/2019 10:52 .

The Health Research Ethics Committee reviewed and approved the annual progress report through an expedited review process. The approval of this project is extended for a further year.

Approval date: 23 October 2019

Expiry date: 22 October 2020

Kindly be reminded to submit progress reports two (2) months before expiry date.

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, *Infonetica*, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: https://applyethics.sun.ac.za.

Please remember to use your Project Id 7662 and ethics reference number S18/07/151 on any documents or correspondence with the HREC concerning your research protocol.

Yours sincerely,

Mrs. Melody Shana

Coordinator

Health Research Ethics Committee 1

National Health Research Ethics Council (NHREC) Registration Number:
REC-130408-012 (HREC1)•REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1)•IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2006).Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

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Approval Letter
Progress Report

20/11/2020

Project ID: 7662

Ethics Reference No: S18/07/151

Project Title: Exploring Fatigue amongst Individuals Living with Multiple Sclerosis: A South African PerspectiveDear

Mr Nicolaas van Niekerk

We refer to your request for an extension/annual renewal of ethics approval received 12/11/2020.

The Health Research Ethics Committee reviewed and approved the annual progress report through an expedited review process. The

approval of this project is extended for a further year.

Approval date: 20 November 2020

Expiry date: 19 November 2021

Kindly be reminded to submit progress reports two (2) months before expiry date.

Where to submit any documentation

Kindly note that the HREC uses an electronic ethics review management system, *Infonetica*, to manage ethics applications and ethics review process. To submit any documentation to HREC, please click on the following link: https://applyethics.sun.ac.za.

Please remember to use your Project Id 7662 and ethics reference number S18/07/151 on any documents or correspondence with the HREC concerning your research protocol.

Please note that for studies involving the use of questionnaires, the final copy should be uploaded on Infonetica.

Yours sincerely,

Mrs. Melody Shana
Coordinator: Health Research Ethics Committee 1

National Health Research Ethics Council (NHREC) Registration Number:
REC-130408-012 (HREC1)·REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1)•IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2006).Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

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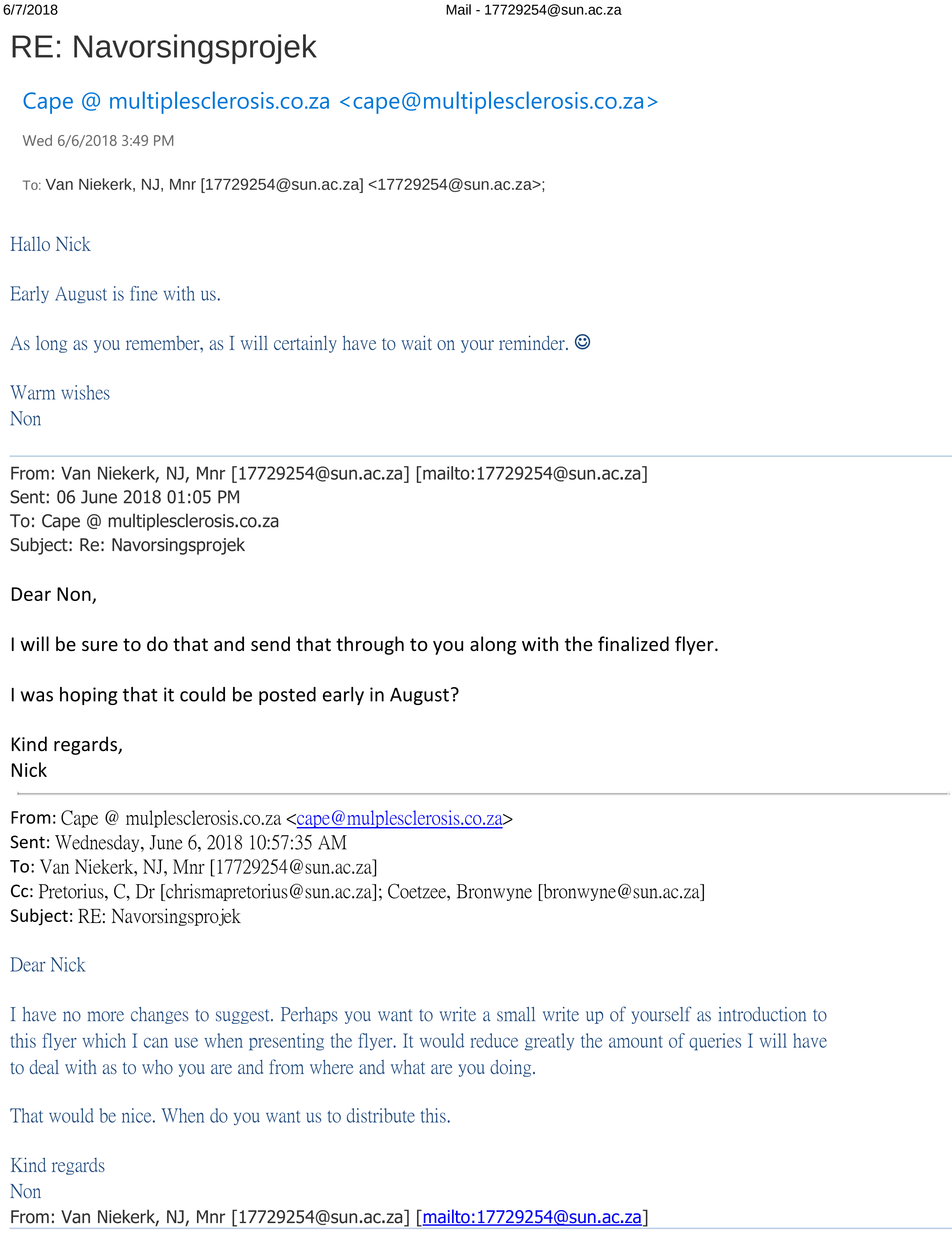
Appendix N: Communication with the Director of MSSA’s Western Cape Branch



6/7/2018 Mail - 17729254@sun.ac.za

RE: Navorsingsprojek

Cape @ multiplesclerosis.co.za <cape@multiplesclerosis.co.za>

Wed 6/6/2018 3:49 PM

To: Van Niekerk, NJ, Mnr [17729254@sun.ac.za] <17729254@sun.ac.za>;

Hallo Nick

Early August is fine with us.

As long as you remember, as I will certainly have to wait on your reminder. ☺

Warm wishes
Non

From: Van Niekerk, NJ, Mnr [17729254@sun.ac.za] [mailto:17729254@sun.ac.za]
Sent: 06 June 2018 01:05 PM
To: Cape @ multiplesclerosis.co.za
Subject: Re: Navorsingsprojek

Dear Non,

I will be sure to do that and send that through to you along with the finalized flyer.

I was hoping that it could be posted early in August?

Kind regards,
Nick

From: Cape @ mulplesclerosis.co.za <cape@mulplesclerosis.co.za>
Sent: Wednesday, June 6, 2018 10:57:35 AM
To: Van Niekerk, NJ, Mnr [17729254@sun.ac.za]
Cc: Pretorius, C, Dr [chrismapretorius@sun.ac.za]; Coetzee, Bronwyne [bronwyne@sun.ac.za]
Subject: RE: Navorsingsprojek

Dear Nick

I have no more changes to suggest. Perhaps you want to write a small write up of yourself as introduction to this flyer which I can use when presenting the flyer. It would reduce greatly the amount of queries I will have to deal with as to who you are and from where and what are you doing.

That would be nice. When do you want us to distribute this.

Kind regards
Non
From: Van Niekerk, NJ, Mnr [17729254@sun.ac.za] [mailto:17729254@sun.ac.za]

Sent: 06 June 2018 10:21 AM
To: Cape @ multiplesclerosis.co.za
Cc: Pretorius, C, Dr [chrismapretorius@sun.ac.za]; Coetzee, Bronwyne [bronwyne@sun.ac.za]
Subject: Re: Navorsingsprojek

6/7/2018 Mail - 17729254@sun.ac.za

Dear Non,

Thank you for your input. I have altered this in the flyer to be more clear on that point. It now reads as follows:

1. That do not have a current relapse or had a relapse in the last three months

Let me know if there are any other alterations I can make

Kind regards,
Nick

From: Cape @ mulplesclerosis.co.za <cape@mulplesclerosis.co.za>
Sent: Monday, June 4, 2018 6:41:42 PM
To: Van Niekerk, NJ, Mnr [17729254@sun.ac.za]
Cc: Pretorius, C, Dr [chrismapretorius@sun.ac.za]; Coetzee, Bronwyne [bronwyne@sun.ac.za]
Subject: RE: Navorsingsprojek

Dear Nick

You are most welcome. We welcome studies originating from and under the supervision of Dr Chrisma Walters.

I would agree with what you propose. We will be posting your flyer in the group and encourage members to participate.

Maybe you can be more specific in terms of your criteria in this item:

That do not have a current, or had a recent, relapse

How recent? As that will narrow down the criteria substantially.

Kind regards
Non

From: Van Niekerk, NJ, Mnr [17729254@sun.ac.za] [mailto:17729254@sun.ac.za]
Sent: 04 June 2018 06:17 PM
To: cape@multiplesclerosis.co.za
Cc: Pretorius, C, Dr [chrismapretorius@sun.ac.za]; Coetzee, Bronwyne [bronwyne@sun.ac.za]
Subject: Re: Navorsingsprojek

Dear Non,

I hope this email finds you well. My name is Nick van Niekerk and Bronwyne and Chrisma are my M-thesis supervisors.

I am about to submit my proposal for review, and just wanted to provide you with more details of my study.
My study will explore fatigue amongst individuals living with MS in the Western Cape.

I would like to conduct telephonic interviews with interested participants (between 10 and 20 interested individuals), whom I would like to recruit via the MS Society’s Facebook page. I would be grateful for your assistance in this regard.

I will develop a flyer (which must first be approved by our ethics committee) which I would like to send to you to please place on the FB group. I have attached a copy of the flyers content for you to look at. The flyer contains my details, and interested participants can make contact with me directly and I will then perform a screening for study eligibility, and then arrange an interview date and time.

I hope this brief description provides you with an overview and understanding of what I am aiming to do. Please let me know if you would like more details?

Please could you let me know whether you are still willing to assist with the recruitment process by posting the flyer on the FB group? Additionally, should you have any further questions or comments please do not hesitate to contact me.

I'm looking forward to hearing from you, and thank you for your support.

Kind regards,
Nick

Appendix O: Informed Consent Form

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

Exploring Fatigue amongst Individuals Living with Multiple Sclerosis: A South African Perspective

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Nicolaas Jacobus van Niekerk

SUPERVISOR: Dr Bronwyne Coetzee

CO-SUPERVISOR: Dr Chrisma Pretorius

ADDRESS: The Department of Psychology, Faculty of Arts and Social Sciences,Stellenbosch University Main Campus

CONTACT DETAILS: Dr Coetzee (021 808 3979); Dr Pretorius (021 808 3453);
Mr. van Niekerk (072 398 2130; Nickvn@outlook.com)

You are being invited to take part in a research project. Please take some time to read through the information presented here, which will explain the details of this project. Please ask the principal investigator or his supervisor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you sayno, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study atany point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

- The Aim and Purpose of this study:
    - *This study seeks to explore what it is like to live with fatigue from the perspective of people with Multiple Sclerosis (MS) in the Western Cape. More specifically, it will explore how people with MS perceive and make-sense of living with fatigue by interpreting their descriptions of: (1) fatigue as a symptom, (2) how fatigue impacts on daily life, (3) how fatigue and its impacts on daily life are coped with and managed. Through this, this research project seeks to: (1) develop an in-depth understanding of fatigue as experienced by people with MS, (2) inform the development of more person-centred clinical responses and psychological interventions for people with MS suffering from fatigue*
    - *This research project will be conducted for degree purposes and to meet the degree requirements for an MA (Psychology) by thesis.*

- What will be asked of me should I consent?
    - *Should you agree to participate in this research you will be asked to participate in an individual interview over the phone. If however you feel uncomfortable with a telephonic interview, you will be asked to participate in either a Skype interview or an at home face-to-face interview (provided you live within ± 50 km drive from Stellenbosch). The interview will be conducted in English by the primary investigator at a prescheduled date and time that suits you. The interview will take between 30 minutes to 1 hour to complete, and will be recorded for transcription purposes (i.e. to be written down from audio into a hard-copy format).*
    - *Immediately after the interview you'll also be asked to complete a few questionnaires. These questionnaires will collect some demographic data as well as clinical data on your MS diagnosis, fatigue, and other potential causes of fatigue. The questionnaire should take no longer than 25 minutes.*
- Study Procedure:
    - *Up to 20 individuals suffering from MS with self-reported moderate to severe fatigue who meet certain criteria (see section: why have I been invited to participate) will be asked to take part in individual interviews. Following their participation in the interviews the audio-recordings will be transcribed by a transcriptionist who: (1) will sign an agreement with the investigator to ensure confidentiality, (2) won't have access to any of your information collected through the questionnaire, (3) won't play a role in the research beyond transcribing. Hereafter, the primary investigator will analyse the information of the participants gained through the interviews.*

Why have you been invited to participate?

- *You have been invited to participate in this study since your answers to the pre-selection questionnaire show that you meet criteria to be included in this study. These criteria you have met are as follows:*
    - *You are older than 18 years old*
    - *You live in the Western Cape*
    - *You have been diagnosed with MS*
    - *You have had an MS diagnosis for longer than 1 year*
    - *You self-reported that you experience moderate to severe fatigue*
    - *You do not have a current MS-related relapse*
    - *You have not had a MS-related relapse in the last three months*

What will your responsibilities be?

- *It is essential that you read through the entire consent form and ask the primary investigator any questions you may have for further clarity on the research project*
- *Ensure that you understand the process of the study prior to giving your consent*
- *Please take note of the potential risks and benefits of taking part in this research project.*
- *Be aware that should any harm or distress arise as a result of your participation in this investigation, referral information has been provided.*
- *It is required that you understand how your identity, information, and confidentiality will be protected.*
- *Should you wish to discontinue or retract your participation, do not hesitate to communicate this to the primary investigator. There will be no consequences to your withdrawal.*
- *If you have any concerns around or problems with the study, please don't hesitate to contact the primary investigator, supervisor, or co-supervisor.*
- *Should you decide to participate, please sign this form and email it to the primary investigator (Nickvn@outlook.com). Thereafter I will sign and email a copy back to you for you to keep as an information sheet regarding the study.*

Will you benefit from taking part in this research?

- *Participants will not benefit financially from their participation in this research study. However, this project will address a gap in knowledge on fatigue in MS by developing an understanding of fatigue from the perspective of people with MS within the Western Cape. Additionally, the study may inform the development of more person-centred clinical responses and psychological interventions for people with MS suffering from fatigue. Furthermore, through an engagement within the interview process participants may gain a deeper awareness and understanding of their experiences of living with fatigue.*

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

- *This is a medium risk study. Note that it is possible that the interview process and/or certain questions may elicit some psychological and/or emotional discomfort when you answer them. Should your participation in the research and/or the interview process elicit significant psychological distress, fatigue or emotional discomfort you may communicate your needs to the interviewer. Such needs include, but may not be limited to, the need to take a break or discontinue/retract your participation, not answer a question.*
- *If you need psychological support because of psychological and/or emotional distress that arises as a result of participation in the research and/or the interview process please contact Welgevallen Community Psychology Clinic for: (1) free face-to-face clinical services in Stellenbosch, (2) free psychological support over the phone and additional information on psychological services near where you live.*
    - *Contact details:*
        - *Physical Address:*
          Welgevallen Community Psychology Clinic
          Welgevallen House
          Suidwal Street
          Stellenbosch
        - *Website: www.sun.ac.za/wcpc*
        - *Tel: 021 808 2696*
        - *Email: wcpc@sun.ac.za*
- *If you need support surrounding your MS diagnosis please contact Multiple Sclerosis South Africa's (MSSA) Western Cape branch for: (1) telephonic/email support, (2) and/or access to their online Facebook support group.*
    - *Contact details for MSSA's Western Cape support services:*
        - *Tel: 021 948 4160 (provides 24/7 support)*
        - *Email: info@multiplesclerosis.co.za*
    - *For access to MSSA's online MS support group on Facebook follow the following link:*
        - *https://www.facebook.com/groups/msgroupsa/*
    - *Website: http://www.multiplesclerosis.co.za/*

If you do not agree to take part, what alternatives do you have?

- *Participation within the study is entirely voluntary. As such, you may choose to participate in this investigation without any consequence to you. Additionally, please note that you are also free to discontinue your participation at any time and even after giving consent.*

Who will have access to your medical records?

- *This research project does not require access to any medical records*

Will you be paid to take part in this study and are there any costs involved?

- *You will not be paid to take part in this research study and your participation will not require any financial costs on your part. All charges related to conducting interviews will be the responsibility of the primary investigator. More specifically:*
    - *In the case of a telephonic interview:*
        - *I will carry the network charges related to the telephonic interview and the completion of the questionnaire by calling you at the prescheduled date and time.*
    - *In instances where Skype interviews are requested:*
        - *I will reimburse you with 1 GB for your data costs related to the Skype interview and the subsequent completion of the questionnaire.*
    - *In instances where an at home face-to-face interview is requested:*
        - *I will carry the petrol costs to drive through to you for the at home face-to-face interview and subsequent completion of the questionnaire.*
- *Should you choose to participate, I will also send you a R100 Takealot gift voucher nearing the end of my MA degree as a small gesture of my gratitude and appreciation for your effort and time put into participating in this study.*

In what ways will you identity, information, and confidentiality be protected?

- *Any information you share with me during this study and that could possibly identify you as a participant will be protected. This will be achieved through an adherence to the following six strategies:*
    1. *Whilst the primary investigator cannot ensure complete anonymity on his part, he will ensure that the interview information remains confidential whilst anonymizing the data (by assigning code identifiers to participants) when analysing the transcripts and reporting findings.*
    2. *The audio-recordings and interview transcripts will only be accessible to the primary investigator, his supervisor, and the co-supervisor. Additionally, these documents will be encrypted and stored on a password protected computer to further limit accessibility.*
    3. *Please note that whilst the transcriptionist will require temporary access to the audio recordings for transcription purposes, he/she will sign an agreement to keep the content of your interview confidential. Additionally, this agreement will also necessitate the deletion of all such data possessed by him/her upon my request.*
    4. *The information collected in achieving the aims of this study will not be disclosed to any agency, party, or individual that is not the supervisor, co-supervisor, or transcriptionist.*
    5. *Your contact details will not be used for any purpose beyond that specifically relating to conducting and completing the research.*
    6. *Upon completing and submitting the research project, all data collected will be kept for a minimum of 5 years as per policy of the University of Stellenbosch.*
    7. *The results and findings of this research study may possibly be used for a publication. If this should realise, your information will be protected through the continued adherence to the points highlighted above.*

Is there anything else that you should know or do?

- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I …………………………………………………agree to take part in a research study entitled: Exploring Fatigue amongst Individuals Living with Multiple Sclerosis: A South African PerspectiveI declare that:

- I have read or had read to me this information and consent form and it is written in a languagewith which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to takepart.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- All issues related to privacy, and the confidentiality and use of the information I provide, have beenexplained.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my bestinterests, or if I do not follow the study plan, as agreed to.

By signing below, I_________________________________*(name of participant)* agree to take part in thisresearch study, as conducted by Nicolaas Jacobus van Niekerk

____ ______________________

Signature of Participant **Date**

Declaration by the principal investigator

I Nicolaas Jacobus van Niekerk declare that:

- I explained the information in this document to …………………………………..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- The conversation with the participant was conducted in a language in which the participant isfluent and hence, I did not use an interpreter.
- I will employ a transcriptionist for the sole purpose of transcribing the audio-recordings ofinterviews.

____ ______________________

Signature of Principal Investigator **Date**

Appendix P: Welgevallen Community Psychology Clinic's Willingness to Mitigate Risk

WELGEVALLEN COMMUNITY PSYCHOLOGY CLINIC
Department of Psychology, Stellenbosch University
Tel: 021 808 2696 Email: wcpc@sun.ac.za Web: www.sun.ac.za/wcpc

12/06/2018

RE: Free Psychological Services

The Welgevallen Community Psychology Clinic is a clinic offering free psychological services to people in need within the greater Stellenbosch area.

This letter serves as confirmation that the clinic services are available to provide support to any research participants who may experience psychological distress during or due to participation in the research being conducted by Nick van Niekerk. The clinic will provide telephonic assistance and information about psychological clinics in their immediate vicinity, should an individual be unable to attend sessions in Stellenbosch, due to their geographical position.

The abovementioned research student is conducting his research under the supervision of Dr. Bronwyne Coetzee and Dr. Chrisma Pretorius.

His research will be focused on exploring fatigue amongst individuals living with multiple sclerosis.

The aforementioned researcher agrees to provide the clinic details to all research participants to ensure that they are aware of the support available, and are thus able to access the necessary support should the need arise.

Please do contact me for further information

Megan Snow
Clinical Psychologist
Clinic Manager
Welgevallen Community Psychology Clinic
Stellenbosch University

Web: www.sun.ac.za/wcpc Tel:
021 808 2696
Email: wcpc@sun.ac.za

Appendix Q: MSSA's Willingness to Provide MS-related Psychological Support

RE: MS support group as a referral in managing risk

Cape @ multiplesclerosis.co.za <cape@multiplesclerosis.co.za>

Wed 6/13/2018 11:44 AM

To: Van Niekerk, NJ, Mnr [17729254@sun.ac.za] <17729254@sun.ac.za>;

Dear Nick

You are strongly invited to refer participants to MSSA for support and psychological support surrounding their MS diagnosis.

Our 24 hour support line is 021 948 4160 and 082 5505 486 and our email hotline is info@multiplesclerosis.co.za

We have the services of a neuro psychologist inside of our closed support group online on Facebook: https://www.facebook.com/groups/msgroupsa/

M

Non Smit

office | mobile | fax

non@multiplesclerosis.co.za

www.multiplesclerosis.co.za

www.facebook.com/multiplesclerosisSA

@MS_SouthAfrica

NPO # 003-275 – PBO # 9300-175-06

Bank Account Details:

MSSA WC

Standard Bank Acc.# 0730 84 697

Tyger Manor Branch: 050-410

From: Van Niekerk, NJ, Mnr [17729254@sun.ac.za] [mailto:17729254@sun.ac.za]
Sent: 13 June 2018 10:35 AM
To: cape@multiplesclerosis.co.za
Subject: MS support group as a referral in managing risk

Dear Non,

I hope this email finds you well.

I have been looking into support services such as Lifeline and Welgevallen to manage risk linked to participation in the study. I contacted these institutions to provide psychological support (over the phone) should any participant become psychologically or emotionally distressed due to their participation. Welgevallen has agreed to this and also offered to assist participants and identify local and face-to-face psychological support should they need it. Lifeline is still considering whether or not they would be able to assist.

However, I would also like to refer participants to more MS-specific support services when managing risk in this study. I was wondering whether I could refer participants to the MSSA's Facebook support group should they need psychological support surrounding their MS diagnosis?

Best wishes,
Nick

Appendix R: Transcriptionist Confidentiality Agreement

Confidentiality Agreement by Transcriptionist

I *(name)*..........Melandri Constant............declare that:

- I will assist the primary investigator Nicolaas Jacobus van Niekerk through the sole purpose of transcribing the audio recordings, verbatim, for each interview
- I will treat my access to the audio-recordings with the utmost responsibility and sensitivity through: (1) secure storage of electronic copies of the audio-recordings and transcripts, (2) keeping the content and information of the interviews confidential, (3) destroying all copies of audio-recordings and transcripts upon the request of the primary investigator.
- I have agreed to be paid R 3600 in full for fulfilling my role as both a confidant and transcriber.

Signed at (*place*) 4 Logie street Somerset West on (*date*) 08 April 2018..........

.... **Signature of interpreter**

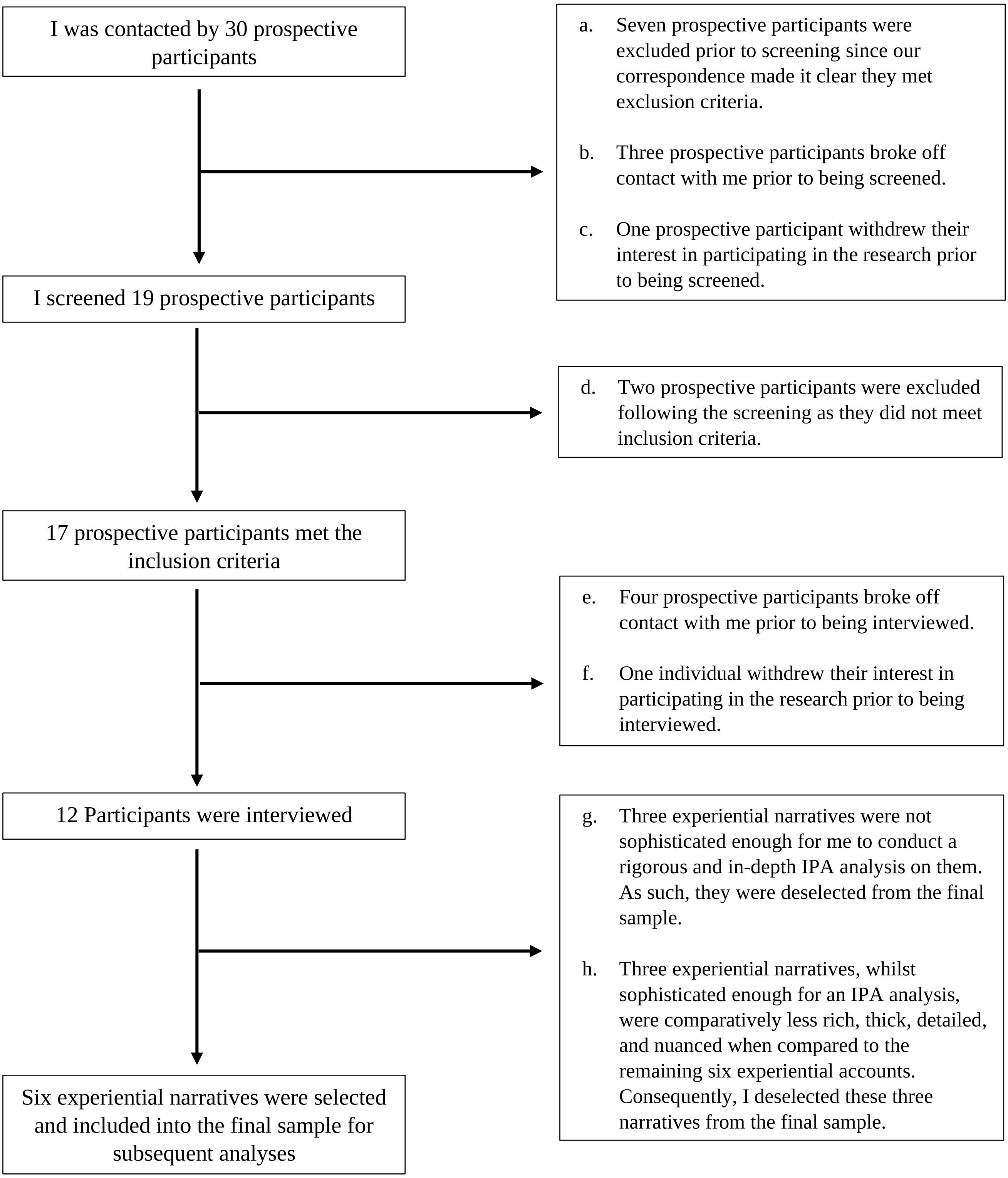
.... **Signature of primary investigator**

.... **Signature of witness**

Appendix S: Overview of Sampling Procedure

Figure S1.

Sampling Procedure as Enacted in the Present Research Study



I was contacted by 30 prospective participants

a. Seven prospective participants were excluded prior to screening since our correspondence made it clear they met exclusion criteria.

b. Three prospective participants broke off contact with me prior to being screened.

c. One prospective participant withdrew their interest in participating in the research prior to being screened.

I screened 19 prospective participants

d. Two prospective participants were excluded following the screening as they did not meet inclusion criteria.

17 prospective participants met the inclusion criteria

e. Four prospective participants broke off contact with me prior to being interviewed.

f. One individual withdrew their interest in participating in the research prior to being interviewed.

12 Participants were interviewed

g. Three experiential narratives were not sophisticated enough for me to conduct a rigorous and in-depth IPA analysis on them. As such, they were deselected from the final sample.

h. Three experiential narratives, whilst sophisticated enough for an IPA analysis, were comparatively less rich, thick, detailed, and nuanced when compared to the remaining six experiential accounts. Consequently, I deselected these three narratives from the final sample.

Six experiential narratives were selected and included into the final sample for subsequent analyses

Figure S1. Illustration of what the sampling procedure in the present study entailed. Vertical arrows demonstrate the sequential process of recruiting participants and selecting narratives for inclusion into the final sample. Horizontal arrows indicate the instances throughout the sampling process where the total pool of cases decreased. Letters (a – h) document the number of, and reason why, cases exited the research process at certain timepoints.

Appendix T: Participants Sense-making of MS-F as a Symptomatic Experience

Table T1

Participants' Sense-making of MS-F through its Symptomatic Features

MS-F as a Lack of Energy
P5: "It's just like it's, almost like your car battery that's, that's gone flat. There's no reserves, that's the best way I can explain it."
MS-F as an Ever-Present Inconsistency of Life
i. Perception of MS-F as a persistent across life
P3: "It's a constant companion; it's not something that goes away. I mean, you can have good and bad days and some days I don't have paraesthesia and some days I don't have vertigo, and some days I don't even have pain but I have fatigue every, every day."
ii. Perception of MS-F as an inconsistency in life
a. Episodic phenomenon
P4: "I have to say to myself, 'P4, it is not your fault, remember who you are in just this moment.'"
b. Variable severity
P3: "Um, it's just the severity that-that changes from day to day."
MS-F as a Mind-body Phenomenon
i. MS-F as mental in in nature
a. Suboptimal mental functioning
P2: "… my brain's not functioning on its optimal level anymore because I'm tired."
b. Mental impairments
P6: "So, it takes a lot of logical thinking to try and work out where the problem is, to try and fix it or get somebody else to fix it. And that logical thought sometimes goes haywire when I'm very tired."

ii. MS-F as physical in nature
a. Physical Incapacitation of the body
P3: “Well, if I had to describe it, it would be… sitting there and realising that if the house started burning, you actually would burn to death because you’re too tired to get up, that’s fatigue. Whereas if you’re tired, you’ll still get up, if you’re fatigued you just, you physically cannot do it.”
b. Altered subjective experience of the physical self
P3: “Sometimes it feels like you don’t belong in your body, like um, you know you – like you don’t fit inside, like your body’s a little bit too small or-or maybe rather actually too big you know. You have this huge thing to carry along, like someone else gave you their outer shell, and you’re inside and you have to carry this whole heavy thing along.”

Note: Bolded text denotes themes and represent those more comprehensive perceptions and perceptual patterns shared by participants. Bolded and italicised text denotes subthemes and signify those more specific, and less comprehensive, perceptions/notions comprised in themes. Lastly, italicised text represents those more descriptive, contextual, and highly specific perceptions/notions which comprised subthemes.

Appendix U: MS-F’s Mental Manifestation

Table U1

MS-F’s Mental Impairments as Described by Participants

Loss of Mental Clarity
P6: “… you come to a point where you’re sort of in a head block, you can’t see past minor obstacles, your sort of stitched up, you can’t see the wood for the trees kind of thing. … It’s like your mind gets cluttered with rubbish, that’s not relevant (pronounced inhalation)”
Impaired Executive Functioning
a. Impaired Concentration
P2: “I was a financial accountant in the state and there you’ve got to be very precise, and you’ve got to concentrate. … I had to be very precise. I had to make sure that I had crossed my ‘t’s’, and you know, like an accountant would. I don’t have that level of conp-cons-concentration anymore…”
b. Impaired Reasoning Ability
P6: “So, it takes a lot of logical thinking to try and work out where the problem is, to try and fix it or get somebody else to fix it. And that logical thought sometimes goes haywire when I’m very tired.”
Impaired Information Processing
a. Impaired filtering of Irrelevant Information
P6: “But you allow yourself to take in information that’s not relevant at all when you’re tired …”
b. Slower Information processing
P1: “You make a connection slower and so, for example if you had to do a math sum, um, you wouldn’t be able to add the numbers up quickly, like you normally could.”
c. Impaired Visual Perception
P2: “… sometimes I can, this thing can be lying next to me, say a pencil and I need to use that pencil. If I ‘m tired I won’t see it straight away, I’ll know it’s there because I just put it down but I’ll have to look a second time because I didn’t see it the first time I’ve looked.”

Impaired Memory Recall
a. Impaired Long-Term Memory
P1: "… you have to actually think about what you're doing. It doesn't just come natural after doing it for like 10 years; you're supposed to be able to just do it in your sleep basically. But this actually – you have to sit, have to think about what you're doing."
b. Impaired Short-Term Memory
P2: "… I don't have much of a short-term memory so I've got to continuously remind myself of doing things 'cause I'll just get up - with the pot on - and get up and walk away and forget about it."
c. Impaired verbal Recall
P2: "They (PwMS) lose their words, their words disappear, it's like it goes into a black hole. And that I also relate to my fatigue, then I know I'm tired."

Note. For participants in this study MS-F could manifest through four categories of mental impairments: (a) loss of mental clarity, (b) impaired executive functioning, (c) impaired information processing, (d) and impaired memory recall. The combination and severity of the mental impairments experienced by participants seemed to vary between participants and alongside changes in MS-F's severity

Appendix V: MS-F’s Presentation through Physical Sensations

Table V1

Physical Sensations of MS-F as Described by Participants

a. Spasms (e.g., jerking, jittering, and twitching)
P2: “… my body twitches and goes into spasms if I’m tired. It’s almost as if like a child who’s not getting enough sleep and they don’t want to go to sleep and they know they have to go to sleep. A child that throws a tantrum, it’s like my body’s throwing a tantrum”
b. Heaviness
P3: “Well, I think it’s-it’s physical like I said, this morning my le- my legs just felt like lead until about 12 o’ clock before that finally let up.”
c. Numbness
P3: “Um, I tend to get more pins and needles in my hands and-and legs when I’m fatigued, yes. The paraesthesia is a little bit increased.”
d. Tingling
P4: “So, the first sensation I have is tingling but it’s a, it’s a fiery tingling so my body almost like fires up.”
e. Nausea
P4: “I can get nauseas; that’s just due to the tiredness.”
f. Physical weakness
P3: “… it’s muscle fatigue as well …”
g. Stiffness
P4: “You know when you stretch your muscle and as you’re stretching your muscle - I’m actually doing it now, I’m bending over and I’m stretching my muscle and … pulling the uh, ja the ligament it’s like a bit of a painful feeling but it’s like a, a nice feeling. So, it’s almost like stretching your ligament.”

Note. *For participants in this study MS-F could manifest through various physical sensations. The precise combination of physical sensations experienced by participants appeared to vary between participants and across distinct MS-F episodes. Furthermore, the sensations of heaviness, weakness, tingling, and spams were highlighted as*

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Appendix W: MS-F's Impacts on Daily Life

Table W1

Participants' Understanding that MS-F Restricts Participation in the World

Restricted Functional Capacity
i. MS-F induced functional Inhibition
P5: "Well, it um, it-it-it prohibits you from doing what you want to do and achieving what you want to do, and achieving what you want to achieve."
ii. Unfeasibility for extensive functioning in everyday life
P5: "… there's a lot of things happening in life and you want to partake and you want to do things, you want to visit places, visit people, visit, do things, ja live. But... and ja, enjoy your hobbies and so on, but at the end of the day you just don't, most of the things you just don't get to because you just, like I said, you don't have the energy to invest in it. So it's ja, it's-it-it's-it feels like, ja. In a way as if life is going on and you're not going along with it."
iii. Unassured Future Functioning
P3: "… some of his friends went to a quiz night the other night that they wanted me to join then I said, "well, I can actually only tell you on Thursday, whether I'll be able to make it or not. … So, that's the way we organise it. I would come at short notice if I could and I would not show if I couldn't."
Loss of Independence
P6: "I can't do any maintenance except check the oil and the water, something like that, something very silly. If it needs work to be done, I must get somebody to do it. There's no self-help anymore."
Loss of Spontaneity
P2: "I can't just on the spur of the moment drop everything, grab a bag and go out, like when I was younger. I've got to plan it…"

Note: Bolded text denotes themes and represent those more comprehensive perceptions and perceptual patterns shared by participants. Bolded and italicised text denotes subthemes and signifies those more specific, and less comprehensive, perceptions/notions comprised in theme