University of
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Experiences of Relapsing-Remitting Multiple Sclerosis and Disease Modifying Treatment

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A phenomenological inquiry

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Abstract

A review of the body of knowledge has provided an insightful overview of the significant strides taken in the field of multiple sclerosis. For instance, the literature has made clear the considerable impact this autoimmune disease can have on an individual and how treatment can modulate the processes that underline this condition. However, this review equally highlighted an absence of literature exploring the experiences of both relapsing-remitting multiple sclerosis and disease-modifying treatment. It is in this context that this thesis is based. That is, this thesis sets out to address this gap in theoretical and clinical practice by employing a methodology and method that would discern individual accounts on the experience of being diagnosed with relapsing-remitting multiple sclerosis and the experience of taking disease-modifying treatment.

Guided by a qualitative research design, semi-structured interviews were undertaken with six participants and analysed using Max van Manen's hermeneutic phenomenological method. For participants diagnosed with relapsing-remitting multiple sclerosis, the analysis organised the discerned themes around four lifeworld existential elements: *Bodily Interruption, Fatigue,* and *Psychological Distress* (corporeality), *Guilt* and *Power Imbalance* (relationality), *Secrecy* (spatiality), and *Death* (temporality). Subsequent themes were discerned in relation to the experience of taking disease-modifying treatment: *Body Object, Decision Dilemma, Pain, Reformulated Life,* and *Complementary and Alternative Medicine* (corporeality) and *Future Orientated* (temporality). These themes, serving as navigators, discerned the manner in which a diagnosis permeated everyday living so that an individual's experience of themselves, of others, and of the world became scientized. Equally, how this encounter with medical terminology influenced treatment decision making and views pertaining to the future.

The discussion addressed the complexity associated to a diagnosis of relapsing-remitting multiple sclerosis (before, during and after) and provided an understanding as to why individuals supplement disease-modifying treatment with complementary and alternative medicine. With this in mind, specific recommendations were suggested: (i) clinicians should give more attention to relapsing-remitting multiple sclerosis as a relational and lived phenomenon, (ii) clinical practice should include discussions surrounding complementary and alternative medicine, and (iii) future research should be developed to the point that the principles of evidence-based disease-modifying treatment practice can be applied to complementary and alternative medicine treatment.

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List of Abbreviations

BPS	British Psychological Society
CAM	Complimentary Alternative Medicine
CNS	Central Nervous System
DA	Discourse Analysis
DMT	Disease Modifying Treatment
GT	Grounded Theory
HCP	Health Care Professional/Professionals
IFNβ-1a	Interferon Beta-1a
IFN-β1b	Interferon Beta-1b
IPA	Interpretative Phenomenological Analysis
MS	Multiple Sclerosis
NICE	National Institute for Health and Care Excellence
PwMS	People/person with Multiple Sclerosis
PwPMS	People/person with Progressive Multiple Sclerosis
PwRRMS	People/person with Relapsing-Remitting Multiple Sclerosis
PPMS	Primary Progressive Multiple Sclerosis
PRMS	Progressive-Relapsing Multiple Sclerosis
PUFA	Polyunsaturated Fatty Acids
RRMS	Relapsing Remitting Multiple Sclerosis
SPMS	Secondary Progressive Multiple Sclerosis
SCT	Stem Cell Treatment
SMT	Symptomatic Treatment
TA	Thematic Analysis
UEL	University of East London

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Above all, I dedicate this thesis to one individual for whom my work – and my life – would simply not be possible without. For her, I cannot think of any words that are good enough to say. To my Mother, this is for you.

In loving memory of

Rakesh Parsottambhai Patel

(24/04/1978 – 14/10/2020)

Chapter One

Introduction

This chapter presents an overview of multiple sclerosis. The intent is to situate the reader into the complex nature of this autoimmune disease in a manner that is digestible. By developing an understanding, the reader is supported in appreciating the burden and consequences of the disease. To meet these endeavours, consideration is equally given to the evolution of treatment. At this point, a question around the effectiveness of treatment may arise in the reader. The answer is a simple one. There is no curative treatment owing to the heterogeneity, chronicity, and limited understanding of disease progression. The intention is to summarise treatment evolution so that an exploration of disease-modifying treatment and specific agents, namely, alemtuzumab, dimethyl fumarate, ocrelizumab, and peginterferon beta-1a can be pursued. The reason for specifying these agents is not arbitrary. It is important to point out here, and as shall be presented in chapter three, these agents were those which were prescribed and experienced by the research participants.

1.1 Multiple Sclerosis

1.1.1 Multiple Sclerosis

> *"Multiple Sclerosis is what a good clinician would call Multiple Sclerosis."*
> *John Kurtzke (1974)*

The often-cited historical landmarks of multiple sclerosis (MS) resemble a tapestry interwoven by a sequence of observations, breakthroughs, and scientific developments. Whilst it is beyond the scope to present here the fabric of that tapestry from paralysis to paraplegia *sclérose en plaque disseminée,* a comprehensive history is provided by Murray (2005).

The earliest recorded description of a case of MS dates back to 1421. Aged sixteen, Saint Lidwina of Schiedan (1380-1433) displayed a prognosis consistent with MS having fallen and broken a rib whilst ice-skating. Later, Sir Augustus d'Este (1794-1848) documented his own twenty-six-year undiagnosed experience of ill-health that emerged after a bout of measles. In his diary, he recorded experiencing fatigue, visual impairment, numbness below the waist, and a progressive loss of motor control (Milo & Miller, 2014). Shortly afterwards, the Scottish pathologist Robert Carswell (1793-1857) in the *Atlas of Pathology* (1838) identified lesions in the spinal cord but did not attribute the detected lesions to MS. As an early illustrator, he wrote "a peculiar disease state of the chord and pons varolii, accompanied with atrophy of the discoloured portions" (1838, p.110). In the same period, the French anatomist Jean Cruveilhier (1791-1874) put forward the pathological features of 'disseminated sclerosis' having studied the case of a female patient who presented with dysphagia, spasms, visual impairment and weakness in her limbs. However, according to Murray (2006), it is the German pathologist Friedrich von Frerichs who can be regarded as having made the first diagnosis of MS in 1849. This "brilliant correctness of diagnosis" (Reese, 1950, p.1471) was later authenticated by his student Valentiner in 1856. Most recognisably, it was Jean-Martin Charcot at the Salpétrière Hospital in Paris who embarked on the study of human demyelinating disease. Charcot made definite the association between symptomatology and the pathological changes in this disease through research published in 1868, and in later published lectures and clinical presentations. He understood this disease as "*sclérose en plaques disseminées*", "*la sclérose multiloculaire*" and “*la sclérose generalisée”* (Charcot, 1868a; 1868b; 1872; 1875; 1886; 1887). As these terms were translated, the German term *multiplen sklerose* arose. Translated into English, *multiple sclerosis* became widely accepted following the publication of the landmark text *Multiple Sclerosis* (McAlpine et al., 1955). Specifically, the term *sclerosis* means scars/scarring, and which denotes the damage inflicted onto the nerves by MS. *Multiple* refers to the frequency of occurrence in various areas of the central nervous system (CNS).

Throughout this thesis and notwithstanding the rich history conceptualising MS (Talley, 2004), the term *multiple sclerosis* has been applied for continuity. This has been the case even in reference to the work of contributors who may themselves have adopted alternative terms.

1.1.2 Pathophysiology, Symptoms and Classifications

Pathophysiology

MS is an autoimmune, inflammatory, demyelinating and neurodegenerative disease of the CNS (D’Amico et al., 2016; Reich et al., 2018). Why these characterizations transpire is a mystery. The general rubric that has pervaded literature is that “for some reason, the body fails to recognize the myelin [sheath] as its own and destroys it” (Beaumont, 2008, p.161). Myelin which is considered to be the protective coating around the nerve axon (part of a nerve cell which transmits nerve impulses away from the cell body) is damaged by autoreactive T-cells (a component of the adaptive immune system) (*see* Figure 1.) which cross the blood-brain-barrier. The subsequent events culminate in demyelination which leads to the slowing, disruption and/or blockage of action potentials travelling through the nerve axon (Calabresi, 2004; Compston & Coles, 2008). Another key element is the long-term level of demyelination. Subsequent remyelination is not uncommon and to a certain degree can explain the remission that may occur after a relapse. Yet, it is in this respect that remyelinated nerve axon(s) can be understood as operating as normal as symptoms clear, but studies have shown conduction to be slower than normal (Murray, 2005). Consequently, the demyelination and remyelination patterns result in sclerotic plaque(s) that develop in various regions of the CNS. Therefore, according to Compston and Coles (2008), over time MS develops as a disease of chronic neurodegeneration rather than acute pathological inflammation. However, the debate remains as to whether a single mechanism is exclusively accountable for instigating disease pathophysiology or whether various mechanisms occur simultaneously.

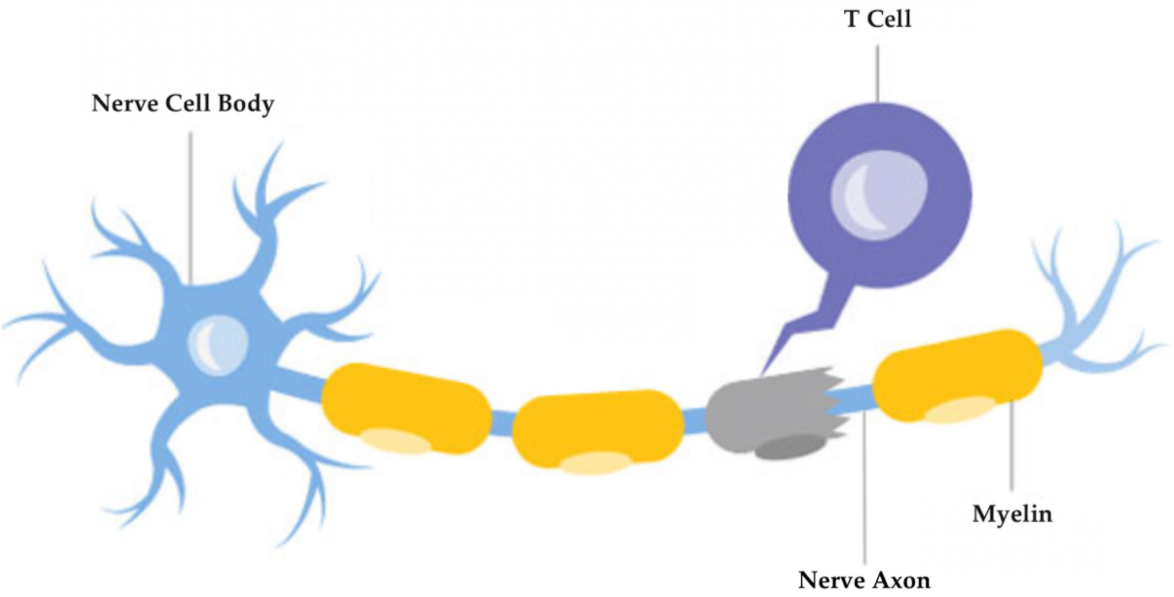


Figure 1. Illustration of the pathophysiology in MS.

Symptoms

Presenting a comprehensive account of the signs and symptoms of MS would neglect the difficulties associated with the intricacies of individual symptom recognition. In the absence of such information, symptoms in virtually every advanced case of MS can be the direct result of "nerve axon conduction issues secondary to demyelination, responses to acute relapse, or as a long-term consequence of previous demyelination and axonal injury" (Burke, 2019, p.25-

26). According to McAlpine et al. (1955), commonly affected sites to produce symptoms are the optic nerves, the cervical portion of the spinal cord and the brainstem. This symptomatology can vary greatly, occur in isolation or in combination, be the result of a sudden relapse or as part of a steady progression (Crayton & Rossman, 2006; Newland et al., 2016).

Clinical manifestations of MS are dependent on the anatomical site affected by demyelination but will typically include disturbances of the visual pathway (e.g., acute optic neuritis), sensory disturbances (e.g., cortical sensory loss), paroxysmal symptoms (e.g., trigeminal neuralgia), autonomic nervous system symptoms (e.g., bowel and/or bladder dysfunction), motor disability (e.g., fatigue), and disturbances of cognition. Clinical manifestations researched frequently are neuropsychiatric' symptoms (Compston, 2005; Mitolo et al., 2015; Motl et al., 2008). For instance, Garfield and Lincoln (2012) implicated a role of depression, low levels of self-efficacy, and stress to increase the possibility of anxiety amongst people with MS (PwMS). Equally, studies have shown fatigue to be a common experience for PwMS (Bakshi et al., 2000; Capone et al., 2019; Krupp, 2003). Specifically, research has shown fatigue to affect up to 80% of PwMS (Leocani et al., 2008; Tur, 2016) and can be regarded as the most disabling symptom (Capone et al., 2019). Other studies have highlighted MS-related fatigue to be complex, multidimensional, poorly understood (Smith et al., 2013) and a constantly paralyzing force (Newton et al., 2016).

At this point, whilst a detailed exposition of MS symptomology is beyond the scope of this thesis, readers are advised that many symptoms are often not noticeable. Therefore, symptoms, at times, are expressed as "hidden" or "invisible", which often leads to conceivable stigmatisation and inadequate understanding (Joachim & Acorn, 2000).

Classifications

Although the course of MS is variable, two distinct phenotypes can be discerned; the progressive phenotype (including primary-progressive MS and secondary-progressive MS) and the relapsing phenotype (including progressive-relapsing MS and relapsing-remitting MS) (*see* Figure 2).

Primary-Progressive MS (PPMS)

PPMS affects 10%-20% of the overall MS population (Miller & Leary, 2007; Milo & Miller, 2014; Tsang & Macdonell, 2011) with an average onset age of forty years (Kamm et al., 2014). In short, PPMS is characterized by a gradual uninterrupted decline of neurological functioning from symptom onset without distinct exacerbation and/or relapse occurrence (Lublin et al., 2014; Talbot, 2010).

Secondary-Progressive MS (SPMS)

In the relapsing-remitting phenotype, neurological sequelae from relapses results in incomplete recovery and accrual of disability over time (Compston & Coles, 2008; Rovaris et al., 2006). In contrast, the hallmark of SPMS is an “initial relapsing remitting disease course followed by progression with or without occasional relapses, minor remissions, and plateaus” (Lublin & Reingold, 1996, p.907–11). With this in mind, Tremlett et al. (2008) have suggested that SPMS occurs approximately twenty years after the onset of relapsing remitting MS.

Progressive-Relapsing MS (PRMS)

As the least prevalent phenotype of MS, PRMS is characterized by a progressive deterioration of neurological functioning from symptom onset, a subsequent superimposed distinct acute relapse with or without full recovery, and a continuous disease progression in-between phases of relapses (Tullman et al., 2004). It is believed further disability is accrued due to incomplete recovery from acute relapse and/or exacerbation (Lublin & Reingold, 1996).

Relapsing-Remitting MS (RRMS)

Based on research, RRMS affects 85% of PwMS (Castro et al., 2020) and is commonly diagnosed between the age of eighteen and forty years (Compston & Coles, 2008). This phenotype of MS is characterized by unpredictable relapses often evolving over days to several weeks before a resumption to baseline (before the relapse) functioning and followed by periods of stable neurological functioning (i.e., symptomatic remission) (Lublin et al., 2014). Typically, recovery from a relapse and a resumption to baseline functioning occurs over a period of four to eight weeks (Sorensen et al, 2014). However, uncertainty, variability and incompleteness remain common. Compston and Coles (2008) have reported that a new relapse can arise unpredictably but seldom arise more than once to twice per year. It is worth recognizing that relapses are defined as a "patient reported or objectively observed event typical of an acute inflammatory event in the CNS, current or historical, with duration of at least twenty-four hours, in the absence of fever or infection" (Polman et al., 2011, p.293).

Alternative phenotypes of MS are known based on clinical features, pathological and imaging appearances, and aetiological considerations. For instance, *benign MS* (BMS), *clinically isolated syndrome* (CIS), *radiologically isolated syndrome* (RIS), *single attack progressive MS* (SAPMS), and *transitional MS* (TMS). With these phenotypes in mind, a study by Lublin et al. (2014) proposed a reclassification based on a relapsing or progressive path, either active or inactive disease, and either progression or non-progression. However, this is yet to be universally adopted.

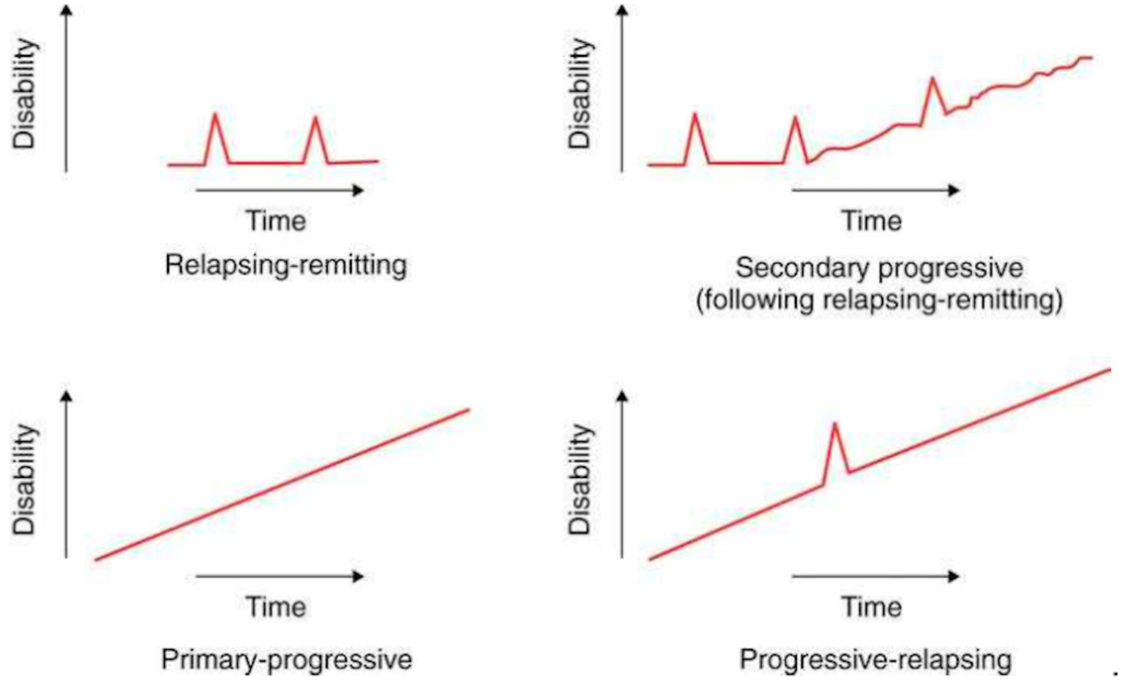


Figure 2. Classification and clinical course of multiple sclerosis based on two distinct phenotypes: the *progressive* course and the *relapsing* course (adapted from Lublin & Reingold, 1996).

1.1.3 Prevalence and Epidemiology

The worldwide prevalence of MS is estimated to be 2.3 million (Brownlee et al., 2016). This prevalence entails the traditional 'latitudinal gradient view' (i.e., increased prevalence farther from the equator) which varies from less than 5/100,000 in low-risk areas (i.e., most of Africa and Eastern Asia) to more than 100/100,000 in high-risk areas (the 'continental gradient view') (i.e., Northern and Central Europe, North America and South-Eastern Australia) (Pugliatti et al., 2002; Sahraian et al., 2012). Similarly, Benito-León and Bermejo-Pareja (2010) support the prevalence of MS being increased in the Mediterranean Basin.

In the United Kingdom, accurate data relating to the number of PwMS remains limited. The MS Society estimate there to be 110,000 PwMS in the UK and approximately 5,200 newly diagnosed individuals per year. These figures indicate a prevalence of 190 cases per 100,000 of the population. Interestingly, McKenzie et al. (2014) attempted to decipher these prevalence trends. Based on data from 2010 and earlier and by coupling primary care and hospital activity records, the researchers' estimated there to be 126,669 PwMS in England in 2010. What this meant was that there was a prevalence of 203 per 100,000 and 6,003 new diagnosed cases at a rate of 9 per 100,000 of the population. However, these focal trends were based on records in which an element of doubt concerning diagnosis existed and hence vulnerable to factors such as the marked variability in symptoms and the subsequent influence on diagnosis. This critique levelled against the findings of McKenzie et al., (2014) can be associated to the work of Minderhoud et al. (1988). In short, Minderhoud et al. (1988) highlight the variable nature of MS progression which means that there exists no common disease course. Thus, in the event that cases of doubt concerning diagnosis were omitted, the resulting number of PwMS in England would be 110,000.

In terms of epidemiology, MS prevalence has a female preponderance in that the disease was more than twice as common in females than males (289 and 115 per 100,000 of the population), females aged between thirty and thirty-nine years were three times more likely than males of a similar age to be diagnosed, the sixty to sixty-nine years of age group for both sexes was identified as having the highest prevalence, and the lowest prevalence was identified as being in childhood which increased after the age of twenty (McKenzie et al., 2014). Equally, according to researchers, MS occurred in approximately 5% of individuals before the age of eighteen (Lulu et al., 2016) and there was an increased prevalence in adolescents compared to younger children (Waldman et al., 2016). It is worth highlighting that research has implicated prognostic features to forecast either a poorer prognosis or an excelled disease progression. For instance, MS was identified as being more frequent among Caucasians (Sahraian et al., 2012) and although Northern and Central Europe, North America, South-Eastern Australia and New

Zealand contained the highest prevalence of MS (Sahraian et al., 2012), ethnicities in these regions appeared resistant (Flachenecker, 2006). This relates closely to studies (*see* Svenson et al., 2007; Williamson et al., 2007) which found MS frequency to differ amongst ethnicities living in equivalent environmental conditions.

1.1.4 Causes

Although no consensus on the cause of MS is available, an amalgamation of features ubiquitous to the developed world may well provide clues to understanding the initiation and development of MS. Polman et al. (2011) categorised these factors into *microbial, viral* and *other infection*. At this point, to re-iterate, the complex nature of the disease indicates toward the unlikelihood of MS resulting from a single causative event (Ramagopalan & Sadovnick, 2011).

Microbial Infection

It is perhaps the hallmark of MS research that microbial infection can be associated to initiating and developing the severity of demyelination in MS (Savarin et al., 2015). The mechanisms of such action can be categorised into two distinct hypotheses. The *poliomyelitis hypothesis* which proposes bacteria assimilated in either late childhood or early adulthood proliferates the probability of MS (Poskanzer et al., 1976), and the *prevalence hypothesis* which demonstrates the cause of MS to be a pathogen commonly associated in populations with increased MS (Kurtzke et al., 1993). It is this pathogen that initiates an asymptomatic persistent infection and later develops into a clinical neurologic MS (Kurtzke et al., 1993). In commenting on the uptake of the microbial infectious agent line of inquiry, the literature has taken favourably to the former hypothesis in comparison to the latter (Bach, 2002; Compston & Coles, 2008; Hunter & Hafler, 2000).

Viral infection

More recently, researchers have substantiated the departure from microbial infection to viral infection in determining the likely cause of MS. For instance, Gilden (2005) found above 90% of PwMS to have increased concentrations of immunoglobulin-G (i.e., a type of antibody) exhibited in the brain and the cerebrospinal fluid. Recently, Hogeboom (2015) concluded the lymphocytic choriomeningitis virus to be harmonious with the mechanisms of MS. Taken collectively, both studies have the potential to explain mechanisms of MS not addressed elsewhere.

Other Infection

Charles Davenport (1922), in a much-cited paper, concluded with the following:

> "In conclusion, may I be permitted the suggestion that whatever may eventually prove to be the endogenous cause of multiple sclerosis, the factor of heredity cannot be left out of account... there are probably internal conditions that inhibit and others that facilitate the development of this disease or the endogenous factors upon which it depends and so it comes about that the manifestations or symptoms of the disease differ in different persons; and that they are sometimes very similar in closely related individuals because the hereditary factors of the constitution in which they operate are similar. It seems most probable that such geographical, ethnological and familial distribution as multiple sclerosis shows depends in part upon one or more hereditary factors" (p.57–58).

Against this backdrop of a hereditary influence, Robertson et al. (1996) found a 2.77% relative-risk in first-degree relatives, a 1.02% relative-risk in second-degree relatives, and a 0.88% relative-risk in third-degree relatives in comparison to a 0.3% relative-risk to the wider population. By carrying this line of inquiry to its logical next step, the study by Ebers et al.

(2004) corroborated with these findings by highlighting the cause of MS to be influenced by the gender of the affected family member.

An association that has diminished over the past decade yet remains relevant is that of the gestational environmental influence on MS. A study showed a greater MS prevalence for individuals born in May and a lessened prevalence for those born in November, within the northern hemisphere (Willer et al., 2005). Studies (*see* Marrie, 2004; Steelman, 2015) have equally shown environmental toxins (i.e., exposure to solvents) to induce MS. For instance, investigations exploring the effects of toxins on MS susceptibility and disease progression have evidenced a correlation between smoking and a probability of conversion to SPMS (Ascherio & Munger, 2007; Marrie, 2004; Pugliatti et al., 2008; Wingerchuk, 2012).

Psychoanalytical Theory

The psychoanalytical and psychodynamic approach has offered an alternative contribution to the study of chronic illnesses. That is, chronic illness is approached from the view that unconscious processes influence personality functioning and it is these processes that are also associated to psychological distress. Alternatively stated, and in contrast to the nosological view, focused is placed on tracing illness to its origins and understanding what is ‘behind’ the overt signs and symptoms (Kernberg, 1988). It is theorized that from “the early stage of development, an individual experiences life in peculiar ways that will progressively determine their identity, including attitudes, coping strategies, cognitive processes, and relational dynamics” (Conversano et al., 2020, p.1). Conceptualising illnesses in this way has facilitated an understanding of the link between the body and the mind and a detection of cyclical relational patterns. For instance, studies have indicated toward a role of personality in the development and progression of psychopathological and organic diseases (*see* Boldrini et al., 2019; Catalano et al., 2019; Martino et al., 2020). Studies have equally explored how personality characteristics can increase the risk of somatic diseases or an individual's general susceptibility to diseases (*see* Denollet et al., 1995; Horwood et al., 2015). Research on individuals who use mature defense mechanisms, “defined as the use of high-adaptive defensive strategies that lead the individual to the best adjustment and possible resolution of internal and external stressors” (Conversano et al., 2020, p.1), have reported higher physical and psychological functioning (*see* Paika et al., 2010; Petric et al., 2011; Perry et al., 2015; Di Giuseppe et al., 2019). Conversely, maladaptive defense mechanisms, “defined as a combination of immature defensive strategies activated to keep the individual unaware of experiencing unmanageable feelings, desires, and thoughts” (Conversano et al., 2020, p.1), have been shown to predict ill-health and acute clinical conditions (*see* Beresford et al., 2006; Bortolato et al., 2017; Hyphantis et al., 2011, 2013a, b; Hyphantis et al., 2016; Conversano et al., 2020).

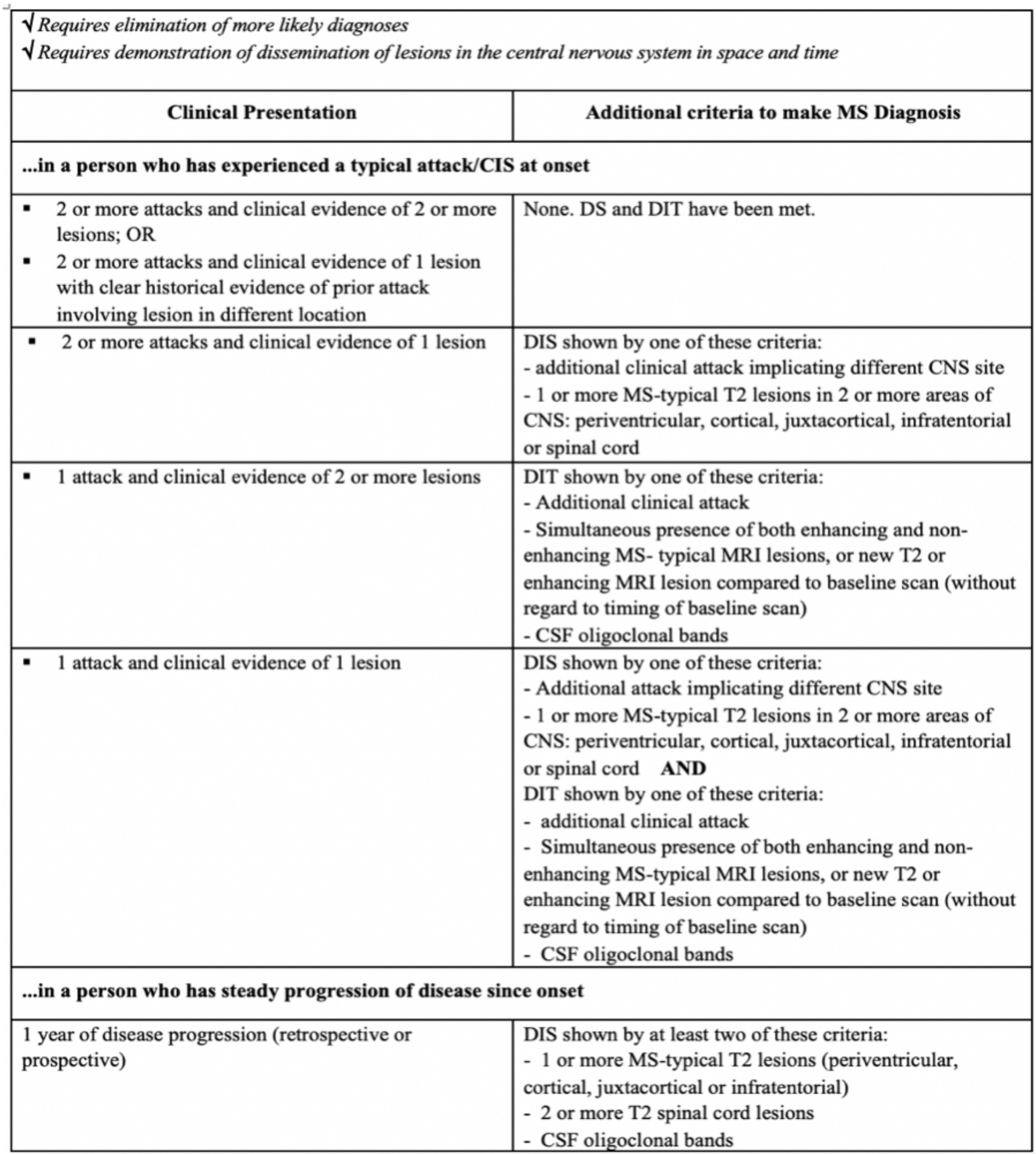
Speculation influenced by psychoanalytical and psychodynamic theory has also emphasised the necessity of recognizing the coexistence of organic and psychological distress. For instance, the biography of Augustus d'Este raises the question of whether emotional arousal over the death of a close relative might be related to the abrupt beginning of ophthalmological symptoms. Equally, Charcot (1872) considered the possibility of psychological trigger mechanisms in MS. Specifically, his work indicated toward a possible association between grief, worry, and adverse changes in social circumstances possibly being causally linked to disease onset. A limited number of reports continued with this line of inquiry. The article titled *Observations on the Psychoanalytical Treatment of a Patient with Multiple Sclerosis* by Leon Wallace (1975) investigated a patient with MS which followed the formal investigations by Jelliffe (1921) who reported the psychoanalytical treatment of his MS patients. Jelliffe (1921) suggested that stress could produce cerebrovascular alterations which might be etiologically related to plaque formation (Al-Afasy, Al-Obaidan, Al-Ansari, Al-Yatama, Al-Rukaibi, Makki, Suresh, & Akhtar, 2013). In addition to the exact mechanistic pathway of this relationship not yet being clearly understood, VanderPlate (1984) argued that "with few exceptions, early psychoanalytically-orientated studies adopted small samples subject to selection bias, employed no standardised objective measures, and drew conclusions about "premorbid personality" and emotional disturbance in MS patients not fully warranted by the data. Few if any conclusions can be drawn for these studies concerning psychological issues in MS" (p.256).

Attempts to consider organic disability as representative of a psychological trauma that may lead to responses that are ordinarily considered neurotic are also available. For instance, neurotic conflicts between dominance and submission which expressed themselves as neurological symptoms have been studied (*see* Langworthy, Kolb, & Androp, 1941; Langworthy, 1948; Langworthy, 1950). As have individuals who could develop organic disability in the context of protracted emotional arousal (*see* Braceland & Giffin, 1950) or anger (*see* Grinker, Ham, & Robbins, 1950). Given that the primary objective of these studies was to describe personality patterns and psychopathology, the general conclusions were that individuals with MS evidenced a high degree of psychopathology and a hysterical personality structure. Other investigators focused on delineation of a uniform MS personality, 'premorbid' psychological characteristics, or emotional response to the disease (VanderPlate, 1984). Nevertheless, given that the evidence to support the association between affective response and MS-related variables is not well understood, few conclusions can be drawn from these investigations. Rather, the consensus believed by most investigators is that psychological response is a complex interaction with wide individual differences.

1.1.5 Diagnosis

The challenges associated with diagnosing MS have been well documented (Poser et al., 1983). In the context of this thesis, specific reference is given to the McDonald Criteria of 2017 (*see* Table 1) which reflected the developments in MS evidence, knowledge and practice. According to Mantero et al. (2018), the McDonald Criteria enabled clinicians to; diagnose MS earlier, increase treatment initiation, reduce the risk of disease progression, and identify MS more effectively than previous clinical classification systems allowed. For those interested, Rudick (2011) has outlined both the benefits and drawbacks of this contemporary classification system.

Table 1. The McDonald Criteria (adapted from Thompson et al., 2018).



√ *Requires elimination of more likely diagnoses* √ *Requires demonstration of dissemination of lesions in the central nervous system in space and time*	
Clinical Presentation	**Additional criteria to make MS Diagnosis**
...in a person who has experienced a typical attack/CIS at onset	
▪ 2 or more attacks and clinical evidence of 2 or more lesions; OR ▪ 2 or more attacks and clinical evidence of 1 lesion with clear historical evidence of prior attack involving lesion in different location	None. DS and DIT have been met.
▪ 2 or more attacks and clinical evidence of 1 lesion	DIS shown by one of these criteria: - additional clinical attack implicating different CNS site - 1 or more MS-typical T2 lesions in 2 or more areas of CNS: periventricular, cortical, juxtacortical, infratentorial or spinal cord
▪ 1 attack and clinical evidence of 2 or more lesions	DIT shown by one of these criteria: - Additional clinical attack - Simultaneous presence of both enhancing and non-enhancing MS- typical MRI lesions, or new T2 or enhancing MRI lesion compared to baseline scan (without regard to timing of baseline scan) - CSF oligoclonal bands
▪ 1 attack and clinical evidence of 1 lesion	DIS shown by one of these criteria: - Additional attack implicating different CNS site - 1 or more MS-typical T2 lesions in 2 or more areas of CNS: periventricular, cortical, juxtacortical, infratentorial or spinal cord **AND** DIT shown by one of these criteria: - additional clinical attack - Simultaneous presence of both enhancing and non-enhancing MS-typical MRI lesions, or new T2 or enhancing MRI lesion compared to baseline scan (without regard to timing of baseline scan) - CSF oligoclonal bands
...in a person who has steady progression of disease since onset	
1 year of disease progression (retrospective or prospective)	DIS shown by at least two of these criteria: - 1 or more MS-typical T2 lesions (periventricular, cortical, juxtacortical or infratentorial) - 2 or more T2 spinal cord lesions - CSF oligoclonal bands

1.1.6 Treatment

No curative treatment for MS is available owing to the heterogeneity, chronicity, and limited understanding of the underlying processes causing disease onset and progression. Therefore, treatment strategy is an area of significant debate. In principle, treatment can either influence symptoms, lessen the occurrence and severity of relapse(s), or reduce brain lesion accumulation

(Stüve & Racke, 2016). Accordingly, treatment strategy can be categorised into either; disease-modifying treatment (DMT) or symptomatic treatment (SMT). The purpose of DMT is to refashion the pathological process underlying MS in a bid to reduce relapse frequency and disease progression (Cree, 2007; DeLuca & Nocentini, 2011). Conversely, by attending to the symptoms caused by MS activity, SMT attempts to; address the symptoms associated with MS lesion location and/or activity, reduce the occurrence of relapse(s), preserve neurological and individual function, and to promote quality of life (Brunton, 2005).

Other

Stem Cell Treatment

Another trend of MS treatment developed over the last twenty years but remains in its infancy is stem-cell treatment (SCT). For those interested, a thorough exploration of the intricacies of SCT is provided by both Pluchino et al. (2009) and Scolding (2011). Stem-cell trials (*see* Atkins et al., 2016; Burt et al., 2015; Liao et al., 2016; Nash et al., 2015) have identified rates of MS free survival to be between 60% and 80%, which is far greater than established treatment. However, of note is the low number of participants in these trials.

Alternative Treatment

Based on the inefficiencies of both DMT and SMT, alternative forms of treatment are frequently utilised (DeLuca & Nocentini, 2011). For those interested, a substantial review of these can be found in the work of Bowling (2011). Often referred to as complementary and alternative medicine (CAM) (Claflin et al., 2018), CAM extends to several types; cannabis (Novotna et al., 2011; Rezapour-Firouzi et al., 2015), physical exercise (Doring et al., 2011; Khan et al., 2008a; Khan et al., 2008b; Taylor et al., 2007), psychological intervention (Mohr et al., 2000; Lincoln et al., 2000; Thomas, et al., 2006) and diet (below). Interestingly, the findings of Claflin et al. (2018) corroborated with previous studies (*see* Farinotti et al., 2007; James et al., 2013; Olsen 2009) in questioning the overall efficacy of CAM. These forms deserve further consideration.

Diet

Epidemiological data has pointed toward a potential effect of vitamin-D (as an immunomodulatory agent) on the clinical course of MS. In a study by Mosayebi et al. (2011) on Iranian PwMS, a six-month vitamin-D intervention was devoid of effect on both symptoms and gadolinium-enhancing lesions in comparison to the control group. However, six-months afterwards, not only was the concentration of cell proliferation significantly reduced subsequent to the vitamin-D intervention in comparison to the control group but the levels of transforming growth factor-beta and interleukin-10 in the treatment group were found to be significantly higher than the control group. These findings warranted further investigation as they provided a preliminary indication toward vitamin-D being a useful addition to treatment as an add-on. Soilu-Hänninen et al. (2008) examined the effectiveness of vitamin-D (as an add-on) in combination to interferon beta-1b (IFN-β1b) and found a reduction in the number of lesions following intervention. However, no effect was found on MS burden and MS disease accumulation.

Two alternative dietary interventions; biotin and ginkgo biloba have also been studied. For thirteen treated PwPMS, disability progression (as measured by the Expanded Disability Status Scale) was reduced following the administration of a high-dose biotin intervention in comparison with placebo. In a follow-up, the biotin intervention-maintained efficacy and the safety profile was parallel to that of placebo. In contrast, study results for the ginkgo extract found no significant effect on neurological functioning compared to placebo (Lovera et al., 2012).

Other CAM include a polyunsaturated fatty acids (PUFA) supplementation in combination with a ‘hot-natured diet’ (originating from customary Iranian medicine in which a ‘heating’ or ‘cooling’ effect is applied to food) (Rezapour-Firouzi et al., 2015). The study identified the PUFA intervention, both with and without a ‘hot-natured diet’, to reduce the relapse rate and reduce disability in PwRRMS over a six-month period (Rezapour-Firouzi et. al., 2015). However, drawing conclusions from these findings can be troublesome as Rezapour-Firouzi et al. (2015) did not provide a statistical comparison between the intervention and control group.

1.2 Disease Modifying Treatment

1.2.1 Disease Modifying Treatment

The history of DMT for MS can be separated into three phases. In the first era (1993–2003), investigations concluded “that intensive immunotherapy could alter the course of MS, and that MS exacerbations could be treated with intravenous methylprednisolone” (Ransohoff et al., 2015, p.2). Distinctively, the second era (2003–2009) was marked by the approval of Natalizumab and Fingolimod (Cohen et al., 2010; Kappos et al., 2006; 2010). Natalizumab (brand name *Tysabri®) “*is a humanized monoclonal antibody which binds to $\alpha_4\beta_1$-integrin” (Hutchinson, 2007, p.1) and inhibits leukocytes from entering the brain via the blood-brain barrier. Conversely, Fingolimod (brand name *Gilenya*®) is an immunomodulatory and immunosuppressive which bind to the receptors of sphingosine-1-phosphate in order to reduce MS activity. By the third era (2009–present), various DMT agents were available for the relapsing phenotypes of MS; interferon beta-1a (IFN-β1a), IFN-β1b, mitoxantrone, natalizumab, glatiramer acetate, fingolimod, dimethyl fumarate, teriflunomide, alemtuzumab, pegylated interferon beta-1a and daclizumab. For the purposes of consideration, the mechanism of action and form of administration of some of these agents have been highlighted (*see* Table 2.). Ultimately, the emergence and availability of agents of DMT provide insights into the complexities involved in deciphering disease progression and treatment.

In summary, an overview of MS has been provided whilst giving consideration to agents of DMT. What follows in the next chapter is more specifically an exploration of the literature.

Table. 2. The mechanisms of action and administration of alemtuzumab, dimethyl fumarate, ocrelizumab, and peginterferon beta-1a

Disease Modifying Treatment	Mechanism of Action	Administration
Alemtuzumab (brand name Lemtrada®)	A monoclonal antibody that binds to the CD52 antigen (a molecule on the surface of lymphocytes and monocytes) resulting in subsequent depletion of B and T lymphocytes.	Alemtuzumab is administered via an intravenous infusion for two initial treatment courses, with up to two additional treatment courses if needed, requiring hospital admission (first treatment course: 12 mg/day on 5 consecutive days, second treatment course after 12 months: 12 mg/day on 3 consecutive days).
Dimethyl Fumarate (brand name Tecfidera®)	Although the mechanism of action in MS is not fully understood, it is thought that dimethyl fumarate works as an immunomodulator (a medication used to regulate or normalize the body's immune system).	Dimethyl fumarate is administered via a twice daily dose of 120 mg orally for 7 days, then increased to the maintenance dose of 240 mg twice daily.
Ocrelizumab (brand name Ocrevus®)	Although the mechanism of action in MS is not fully understood, it is thought that ocrelizumab works as a recombinant humanised monoclonal antibody directed against CD20 antigen expressed by B cells.	Ocrelizumab is administered via an initial 300 mg intravenous infusion, followed 2 weeks later by a second 300 mg infusion. Subsequent doses thereafter are administered as a single 600 mg intravenous infusion every 6 months
Peginterferon Beta-1a (brand name Plegridy®)	There remains limited precision concerning the mechanism of action of peginterferon beta-1a.	Peginterferon Beta-1a is administered via an initial dose of 63lg injected subcutaneously, a second dose of 94 lg injected subcutaneously 2 weeks after the initial dose, and a third and subsequent 125 lg injected subcutaneously 4 weeks after the initial dose and every 2 weeks thereafter doses.

Chapter Two

Literature Review

This chapter presents a background and rationale for this thesis. To begin with, an introduction to the search strategies implemented in identifying the literature relating to relapsing-remitting multiple sclerosis (RRMS) and disease-modifying treatment (DMT) is provided. Next, whilst drawing attention to the vast strides that have been undertaken in understanding the lived experience of people with multiple sclerosis (PwMS), emphasis is placed on explicitly identifying the literature that is pertinent to this thesis. By acquiring a detailed understanding of the literature, the argument is then made that it is possible to discern a gap in the body of knowledge which requires filling. Therefore, making this thesis a timely and relevant piece of work. At this point, the chapter provides a rationale for this thesis. To support this rationale, it is necessary to explicate and contextualize this thesis' contribution and relevance to the practice of counselling psychology. With this all-in mind, the chapter concludes with a statement on the aims of this thesis and the associated research questions.

2.1 Literature Search

This literature review attempted to synthesise the body of knowledge into two fields: (i) the lived experience of RRMS and (ii) the lived experience of taking DMT. The task of collating both quantitative and qualitative research studies began with accessing the following databases:

- EBSCO (2001 - present)
- Elsevier (2001 - present)

- Google Scholar
- PubMed (2001 - present)
- Science Direct (2001 - present)
- Scopus (2001 - present)
- The Cochrane Database (2001 - present)

The search strategy involved the following terms (either singularly or in pairs):

- Multiple Sclerosis OR Primary-Progressive Multiple Sclerosis OR Secondary-Progressive Multiple Sclerosis OR Progressive-Relapsing Multiple Sclerosis OR Relapsing-Remitting Multiple Sclerosis
- Disease-Modifying Treatment OR Disease-Modifying Therapy OR Disease-Modifying Therapies
- Experience OR Lived Experience

The retrieved studies were confined to those available in English and those which stemmed back twenty years. The reasons for which are as follows. As mentioned (*see* 1.1.5 Diagnosis), this thesis incorporated the McDonald Criteria (2017) due to this classification system reflecting the developments in MS evidence, knowledge and practice. Therefore, given that the McDonald Criteria was originally published in 2001, this thesis aspired to capture relevant research papers which may have classified PwMS using either the 2017 or 2001 classification system or even the revisions of 2005 and 2010. On the same line, the search for DMT literature corroborated with the third era of DMT availability (*see* 1.2.1 Disease-Modifying Treatment).

2.2 The Lived Experience of Multiple Sclerosis

Since 2001, a body of knowledge emerged which took a committed stance toward exploring the experience of individuals afflicted by MS. For example, Toombs (2001) provided invaluable phenomenological insights through documenting her own experience of living with MS. Through an exploration which began in 1988 and later in 1990, 1992, and 1995, Toombs eloquently portrayed the spatial distortions shaped by living in a wheelchair. Such portrayals suggested that her experience of MS was primarily a disturbance of the lived body rather than a dysfunction of the biological body. That is, how "features of embodiment as bodily intentionality, primary meaning, contextural organization, body image, gestural display, lived spatiality and temporality, are disrupted" (Toombs, 1988, p.201). Indeed, it was this heightened sense of deeper meaning that made the lived experience of MS accessible to a wider audience. Yet, efforts to produce more contemporary work were required (Burke, 2019).

Several studies have provided meaning and discernment into the lived experience of MS. As per the literature, these sources point to a dynamic personal quest for mastery over the unpredictable disease course. Often, by beginning with the question of 'what was it like to have symptoms of an illness and then to be told you have MS?', studies have shown that this quest begins prior to receiving a diagnosis. For example, Isakkson and Ahlström (2006) reported this initial experience varied from 'disablement and death' and to a 'nuanced picture of MS'. That is:

> "the conception of MS before diagnosis in this patient group was mostly traumatic in nature, independent of earlier experience or knowledge. Statements about being bound to a wheelchair, being handicapped, or dying from MS emerged when the patients described their image of MS before diagnosis" (Isakkson & Ahlström, 2006, p.230).

As the initial symptoms were experienced, these were related to the theme 'becoming vulnerable' which caused emotional distress. Isakkson and Ahlström (2006) reported that as participants attempted to decipher what was happening to them, several experienced ‘anxiety, fear, shame, mistrust, and anger’. Others coped by maintaining a ‘distance and hoping for the best’. Being informed of the diagnosis was discerned to be a prominent part of the participant narratives. This was characterised by the theme ‘from vulnerability to acquired strength’. Furthermore, this experience gave way to more deepened emotions of ‘uncertainty, loss of identity, abandonment, and confirmation’. Although these findings resemble those identified by other studies (*see* Johnson, 2003; McCabe, 2005) and are salient, they are not inevitable.

The interlocking nature of the vicissitudes of ordinary life and the complex lived experience of MS was reported in another study based in New Zealand. Clair (2003) made a telling contribution to the emerging conceptualisation of the lived experience of MS which had so far been characterised by pre-conceptions of MS, a transitory relationship with initial symptoms, an intrusion to the harmony between the body and the self, and diagnosis causing an identity renegotiation. Claire (2003) reported the theme ‘MS as a guest’ which referred to the disease resembling:

> “having an unwelcome houseguest… although the woman did not invite the illness in, once it was there, she needn’t make a fuss but just gets quietly on with her usual day in the hope that the illness will fit into her usual occupational routine” (p.49-50).

At the same time, MS was discerned to be an ‘adversary’. That is:

> “rather than feeling like it should be a fight, illness can inspire the person to overcome the obstacles to doing the things they want and need to do. In these stories the women described needing to be mentally strong in order to stay on guard to the challenge especially when it could present itself at any time” (p.50).

Given the significance of these contributions, it merits noting that these narratives were elaborated and embedded in rich imagery and metaphor and engaged in intuitive story making and storytelling. For instance, a lived experience was described as “it was like living in the twilight zone. You sort of keep it at bay… but it is like having the crew of the Marie Celeste in your hot water cupboard. That is what it is like, that is exactly what it is like. Who knows when they will pop out and see you?” (Clair, 2003, p.50).

More recently, Al-Sharman et al. (2018), in their phenomenological paper titled *Living with Multiple Sclerosis: A Jordanian Perspective*, summarized their reported themes into two main categories; disease-related experiences and experiences related to the healthcare system. Experiences of the former related to ‘physical decline’, ‘psychosocial withdrawal’, and a ‘fear of the future’. On this latter theme, a ‘difficulty of diagnosis’, ‘lack of awareness’, and ‘poor communication and rapport with healthcare providers’ was reported. In the authors’ view, this was “the first study that investigated the daily living experiences and challenges of Jordanian individuals with MS … [The study has] discussed a wide range of issues that represent the lived experiences for living with the disease… such knowledge would provide a background to hidden aspects of human concepts, such as culture, perception, perspectives, attitudes, and opinions about chronic diseases” (Al-Sharman et al., 2018, p.6). Such a claim can equally provide insight into the prevalence and epidemiology of MS worldwide (*see* 1.1.3 Prevalence and Epidemiology).

So far, this chapter has discerned some ideas about the lived experience of MS. These ideas consist of transitory relationships with initial symptoms, an intrusion to the harmony between the body and the self, diagnosis causing identity, relations, and future plans to be renegotiated, and individual attempts to create or maintain a progressive narrative in the face of MS. Such ideas provide a complementary source of themes to that generated by other studies (*see* Evanson et al. 2001, Koopman, 2003; Kroll & Neri, 2003; Maclurg et al. 2004). Before carrying this elucidation to its logical next step, it is important to highlight some of the limitations of the presented studies. In commenting on the study by Al-Sharman et al. (2018) and by considering the geographical region and the associated cultural implications, questions can be raised relating to the applicability of the findings to the western world. Equally, according to Metcalfe (2008), the implication of splitting the participants into groups to facilitate unrestricted dialogue might have been impeded by cultural underpinnings which prevent females from discussing certain elements of their experience in the presence of males. By taking into consideration the recruitment of sixty-one participants in the study by Isakkson and Ahlström (2006), it is important to remember the "bewildering array" (Toombs, 1995, p.7) of symptoms and that each PwMS follows a unique disease course (Minderhoud et al., 1988) (*see* 1.1.2 Pathophysiology, Symptoms and Classifications). Therefore, it seems in practice and in terms of applicability that the study design created by Isakkson and Ahlström (2006) can be brought into question. As can the researchers' decision to not disclose the phenotypes of MS of the recruited participants.

The body of knowledge has benefitted from studies exploring the individual, the individual experience, and the individual relationship with MS (*see* Finlay, 2003; Fawcett & Lucas, 2005). For example, Finlay's (2003) combination of a case study approach and an existential-phenomenological method (Ashworth, 2003; Giorgi, 1985; Valle & Halling, 1989) marked a departure from the previous literature. Yet, it was similar in the sense that the study commenced with the question: 'what is living with MS like for you?'. The study's agency is evident in that Finlay (2003) contributed to the literature by reporting the subsequent themes: sense of self, intersubjectivity and life projects being experienced as threatening and individual identity being reclaimed through living a ‘normal’ present life. In short, such themes provide a complementary source of understanding as the findings are generated through alternative research methods.

Fawcett and Lucas (2005) similarly employed a case study approach to explore a female participant’s journey with MS. That is, from symptom onset to the potential challenges that lay ahead. The following was discerned through the analysis of the data. Firstly, healthcare professionals (HCP), in specific reference to nurses, perform an integral role in the care and experience(s) of PwMS. For example, the recruited participant shared how her initial positive experience was overcome with a felt sense of being a “major inconvenience” as HCP strove to “get through the clinic” (Fawcett & Lucas, 2005, p.48). Secondly, on the same line, understanding the meaning PwMS attribute to their experience “can facilitate the role the nurse and other healthcare professionals can play” (Fawcett & Lucas, 2005, p.51). Thirdly, a crucial element to the experience of the participant was accessibility to information and support. This latter finding corroborated with that of the study published by Embrey (2005).

In critique, there is reason to tread with caution which both studies do not neglect to add. On the one hand, the respective researchers and the research participant were united in friendship prior to undertaking the study. And so, it can be said that this was beneficial to the research process in that it may have aided to the transparency between the two parties. On the other hand, the relationship may have introduced bias and assumed knowledge into the interviewing process. Perhaps, it is for this reason that drawing definite conclusions from both studies can prove to be a challenge. Nevertheless, the case study approach has elucidated the experience of MS to be grounded in lived relations. That is, “through the intertwining, body, self and world” (Finlay, 2003, p.176).

2.3 The Lived Experience of Relapsing-Remitting Multiple Sclerosis

A common thread uniting the qualitative research explored so far is the non-disclosure of the phenotype of MS. By attesting to the view that knowing the phenotype of MS is invaluable to understanding the lived experience, this chapter continues by synthesising the retrieved studies relating to the experience of RRMS specifically.

In her paper titled *the Experience of Young Adults Living with RRMS*, Beshears (2010) adopted a Heideggerian phenomenological method (Heidegger, 1959) which was supported by three subsidiary questions, namely, "for young adults, what is the meaning of changes that might have occurred since the RRMS diagnosis", "how do young adults make meaning of the expectations that others have of them while living with RRMS", and "how do young adults learn new ways of being during periods of exacerbations" (p.20). The following themes were reported: "wishing for an opportunity to talk to others like me, finding that nobody really understands what it is like, wanted to know more about RRMS while not wanting to know too much, seeing life through a new lens, realizing that living with RRMS involved uncertainty, coming to know that RRMS can be scary, discovering that RRMS is frustrating, realizing that planning is important to help maintain a sense of control" (Beshears, 2010, p.80).

In the view that each PwRRMS has their own tapestry of symptoms to master, Beshears (2010) similarly to other studies (*see* Courtney et al. 2009; Fawcett & Dean, 2004; Forwell, et al., 2008; Holland et al., 2009; Howarth, 2000; Ward & Winters, 2003) recognised the variable nature of this common phenomenon. With this in mind, Beshears' (2010) provided a rich contribution to the lived experience of RRMS. That is, the vantage point offered by her study was that previous literature had not reported the theme of 'seeing life through a new lens' which captured how young adults with RRMS found "joy in being able to walk, and …recognizing what is important in life" (Beshears, 2010, p.118). Equally, although the 'inverse association between knowledge and duration of the disease' reported by Beshears (2010) was consistent with previous studies, she went one step further by reporting that PwRRMS sought to learn at their own pace. That is, PwRRMS sought to maintain a sense of control over particular facets of their experience. However, the following limitation points to an intrusion upon the overall inferences that can be elicited from the work of Beshears (2010). With specific reference to demographics, the recruited participants from a rural region of northeast Missouri and central Illinois, were married. Therefore, the themes reported may only be applicable to those females in a similar geographical and relational set-up. But, of course, delimiting the sample in this way was beneficial to understanding experiences that were yet to be explored.

A later study (*see* Pretorius & Joubert, 2014) incorporated a thematic analysis (Braun & Clarke, 2006) to extend the body of knowledge. The authors reported the following main themes and subthemes: 'challenges (main theme); diagnosis, daily life, invisible illness, and medical aid schemes (subthemes)' and 'resources (main theme); social support, mobility aids, religion, and knowledge about multiple sclerosis (subthemes)' (Pretorius & Joubert, 2014, p.5). Interestingly, these themes corresponded with findings from other studies. For instance, the subtheme 'diagnosis', captured not only the majority of participants response to being diagnosed which 'varied between shock and devastation' but how one female participant experienced a positive reaction as it enabled her to understand 'what was wrong with her'. Other emotions which remain embedded in the experience is that of 'shock and devastation' which was supported by findings reported by Barker-Collo et al. (2006) and Malcomson et al. (2008). In addition, the findings reported by Pretorius and Joubert (2014) evidenced that an insufficiency in the communication between the participants and HCP resulted in damaging encounters in terms of the former experiencing a lack of support. Such findings have been reported by Barker-Collo et al. (2006), Edwards et al. (2008), Johnson (2003), and Thorne et al. (2004). Notably, Dalton and Gottlieb (2003) delineated rather succinctly vulnerability initiating strength in instances in which the PwMS felt supported by HCP.

Although the study by Pretorius and Joubert (2014) substantiated important elements pertaining to the lived experience of MS, limitations with their study can be discerned. Similar to a previous study (*see* Beshears, 2010), the study findings cannot be generalised to the wider population. That is, those residing outside of Western Cape, South Africa. On the same line, for some participants, sharing their experience of the diagnosis process may have been inaccurate due to the time frame between the diagnosis and the research interview. Equally, the argument can be made that adopting a thematic analysis can mean interpretations lacking a deeper sense of meaning and a lack of consistency between discerning themes in relation to the lived experience (Smith, 2010). Finally, again, it is unclear which themes apply to which phenotype of MS.

Most recently, Burke (2019) explored the lived experience of PwRRMS. Specifically, the aim of her research was to answer the following research question: 'what is the experience of living with RRMS?'. For Burke (2019), the objective was to explore these experiences along the life trajectory which once taken into consideration would lead to MS nurses having a 'deeper understanding' of PwRRMS. By adopting a thematic data analysis method (Braun & Clarke, 2006), eight primary themes and over seventy subthemes were reported. It is worth recognizing that this unusually high number of themes in a single study makes it difficult to contextualise features of the lived experience of RRMS. The primary themes included: 'piecing together the puzzle (i.e., understanding what is happening); (re) defining me now that I have RRMS; battling the demons (i.e., facing fears and emotions); surplus suffering (i.e., suffering inflicted by HCP); high (in)visibility; taming the beast; the DMT dance (i.e., DMT decision-making); and holding hands with hope' (Burke, 2019). Notably, the theme 'taming the beast' represented a commitment to shape life so that it is expressive and personally significant. That is:

> "a time where they start to conquer the demons they have battled since suffering their first RRMS symptoms, a time where they have gained some experience living with the disease and now have some knowledge about what RRMS actually is and is not. It is a time for positive change, for the beginnings of acceptance, sourcing the best support, sharing tips, gaining confidence and for recognising the incredible things they have achieved… Taming the Beast brings life firmly into the foreground, working to be a person living with RRMS, not an RRMS person. Evolution is key to this theme, as the nature of RRMS means that change is always potentially around the corner and nothing is static" (Burke, 2019, p.264).

With respect to the insightfulness of the themes reported, the study presented with two overarching limitations. As with the case in previous studies, the findings by Burke (2019) are confined to those living in New South Wales, Australia. Therefore, the themes may not be generalizable to women outside of the context of this study. Equally, questions can be raised over the method of inquiry employed. According to Braun and Clarke (2006), as a method, thematic analysis identifies and analyses' themes from a dataset. With this in mind, whether this analysis can discern deeper interpretations can be debated. For Willig (2012), thematic analysis often lacks "an interpretative lens that situates the data within a wider social, cultural and perhaps even theoretic context" (p. 10). Therefore, efforts to utilize a more satisfactory framework remained.

2.4 The Lived Experience of Disease-Modifying Treatment

While much of the literature on DMT is dominated by quantitative investigation (*see* Boake, 2003; Cree, 2007; DeLuca & Nocentini, 2011; Mitchell et al., 2005; Mitolo et al., 2015; Rosti-Otajärvi & Hämäläinen, 2011; Thomas et al., 2006; Wilson, 2008), a paucity of studies exploring the experience of using DMT remains. In this respect and given the degree of attention placed on scientific investigation (*see* Michel et al., 2015), quantitative researchers can be long regarded as the vanguard of DMT literature. However, taking into consideration the trajectory of irreversible disability associated with MS, exploring individual experiences provides a way of considering matters relating to changes in health status and DMT efficacy.

Qualitative studies have explored the experiences of PwMS who have been treated with different agents of DMT (*see* Lowden et al., 2014; Miller & Jezewski, 2001, 2006; Miller et al., 2012; van Capelle et al. 2017; van Reenen et al., 2019). In an interpretative phenomenological analysis (Smith et al., 2009) study of taking oral DMT, namely, Teriflunomide (Aubagio®) and Dimethyl Fumarate (Tecfidera®), van Reenen et al. (2019) identified three phases of experience. In the authors' view, participants with RRMS oscillated between 'trying to hold on to one's familiar life', 'becoming familiar with one's new life', and 'being familiar with one's new life'. In the first phase, van Reenen et al. (2019) point out that this experience is characterised by 'feeling overwhelmed by insecurities, feeling obliged to do something, postponing the constant confrontation with being sick, experiencing support and reinforcement, and doing what fits best personally' (p.4-5). They suggest that the decision to select DMT in an oral form is dependent on various variables:

> "Some people with RRMS decide right away which pill to take, while others thoroughly study the medication leaflets at home, carefully outweighing proposed

> efficacy and potential side effects. Some might make an even more thorough study out of it, by consulting the Internet. The final choice is often based on what "fits" best personally and what is perceived as justifiable to oneself" (p.5).

Other researchers echo these findings. Notably, Miller and Jezewski (2006) explored the experiences of individuals with relapsing forms of MS who self-injected glatiramer acetate (Copaxone®). By applying a Heideggerian phenomenological method (Kockelmans, 1989), a decision to choose glatiramer acetate was based on "the pros and cons of different medications, especially their side effects, was an important consideration in choosing a treatment regimen" (Miller & Jezewski, 2006, p.38). A number of other themes were reported which in many ways remain pertinent to the body of knowledge. These were: "self-managing care, injecting, healthy lifestyle, side effects, support, and advice to others" (Miller & Jezewski, 2006, p.38).

Van Reenen et al. (2019) note that the phase 'becoming familiar with one's new life' consisted of 'awaiting bodily response, familiarizing side effects, adjusting to unpredictability, persevering side effects, establishing a new sense of normalcy, being committed not to forget, and longing for evidence' (p.5-7). During the use of DMT agent, 'adjusting to unpredictability' was referred to as "a major obstacle interfering with daily activities" (van Reenen et al., 2019, p.6) which required "perseverance to give the body time to get used to the drug" (p.6). While a framework through which to view the experience of taking a specific agent of DMT is provided, a previous study has equally portrayed noteworthy conceptualisations. Miller et al. (2012) in a study of PwRRMS receiving natalizumab (Tysabri®) reported five theme categories: "quality of life, switching to natalizumab, uncertainty and fear, avoidance, and social support" (p.40). Notably, the researchers' observed that:

> "Uncertainty and fear are inseparable concepts and are emotions experienced by all of the study participants in some form. Uncertainty is unavoidable in the MS experience and begins with the first symptoms and diagnosis. Then there is the daily uncertainty as to whether the MS will bring a deterioration in function or is actively destroying the patient's nervous system. Patients are never quite certain that they have made the right treatment decisions after weighing the benefits and risks. Fear of the future rings through each of the participants' stories and appears to motivate them to consider stronger therapies with higher risks" (Miller et al., 2012, p.41).

What can be discerned through findings of this nature is at times a high level of agreement with other literature. For instance, the complexity associated to the DMT decision making process was substantiated by previous literature (*see* Johnson et al., 2006; Lowden et al., 2014; Miller & Jezewski, 2001; 2006; van Capelle et al., 2017). In this respect, whilst acknowledging that the findings of each study provided a complementary source of impact and importance (Yardley, 2007), it remains important to note the uniqueness of each study. For instance, the study by van Reenen et al. (2019) was the primary contributor to the body of knowledge pertaining to the experiences of PwRRMS and oral DMT.

According to van Reenen et al. (2019), the last phase 'being familiar with one's new life' was typified by 'finding new meaning, the self-evident use of medication, beyond evidence-based treatment and relinquishing control' (p.7). This living in the 'now' as the new status quo had been reported in previous studies. For instance, Van Capelle et al. (2017) in a study of Dutch PwRRMS and the decision-making process associated to injectable interferon beta 1a (Avonex®), injectable glatiramer acetate (Copaxone®), and tablet form fingolimod (Gilenya®) reported four interrelated themes. These were "constant confrontation with the disease, managing inevitable decline, hope of delaying the progression of the disease, and the importance of social support" (van Capelle et al., 2017, p.4). These themes represented particular interpretations of the lived experience of taking DMT and from the participants perspective showed that starting treatment with DMT was a highly complex phenomenon.

Several limitations can be associated to these studies. For instance, studies (*see* Miller & Jezewski, 2006; Miller et al., 2012) specifically reported findings relating to those individuals who were administered either Glatiramer Acetate or Natalizumab. Thus, it is unclear as to whether the experiences of PwRRMS who are administered alternative DMT agents are similar to those who use either Glatiramer Acetate or Natalizumab. Likewise, it is unclear whether the experience is similar for those who do not experience improvements in MS related ill-health following DMT. A generalisability limitation can be attributed to the study of Miller and Jezewski (2006) as PwRRMS recruited from a different geographic area (i.e., not from Western New York) and a different healthcare setup (i.e., not from an MS centre) may have alternative experiences. In reference to the recruitment process, the recruitment material employed by van Reenen et al. (2019) included the term 'adherence' which due to the normative implication the term bears may have deterred PwRRMS who do not follow the treatment regimen. On this topic of individuality, van Capelle et al. (2017) also attributed an important limitation to their work. That is, the recruited participants stories reflected a "situation of stability in disease course and medication use" (p.8). What this comes to mean is that the study findings may not extend to PwRRMS who encounter alterations to their DMT regimen, experience unanticipated progression in disease course, or treatment failure.

2.5 Rationale for the study

In light of the reviewed literature, it can be said that the experience of PwMS and PwRRMS has long fascinated both researchers and clinicians. Yet, in counselling psychology where human beings and their experiences are viewed “as inherently dynamic, embodied, and relational in nature” (BPS, 2019, p.6), a relatively small volume of literature exists. It is in this context that this thesis attempts to arrive at a deepened appreciation of the experience of being diagnosed with RRMS and the experience of taking DMT. Arriving at this understanding would mean overcoming the limitations of previous research and acknowledging that there remains a diverse array of frameworks and methodologies – both neurological and subjective - that when integrated, can facilitate a multifaceted understanding of both RRMS and DMT.

If only to aid and remind, the limitations of the previous studies were as follows. Studies (*see* Al-Sharman et al. 2018; Clair, 2003; Isakkson & Ahlström, 2006) did not report the specific phenotypes of MS which meant evaluating the transferability of the findings to the wider MS population was problematic. Although Finlay (2003) and Fawcett and Lucas (2005) captured the severity and unique experience of PwMS by adopting an individual case study research design, the limitation of transferability remained due to the respective sample size. Recent studies (*see* Beshears, 2010; Pretorius & Joubert, 2014; Burke, 2019) have offered highly informative insights and understandings into the lived experience of PwRRMS. However, a number of common limitations can be attributed to these studies. For instance, within the realm of demographics; in the study by Beshears (2010) all six participants were ‘white’. Whilst Pretorius and Joubert (2014) did not report ethnicity, generalising their findings to “individuals with relatively-low levels of formal education or from particularly deprived socio-economic backgrounds would be inappropriate” (p.11). In terms of methodological limitations, an interpretative lens was lacking as these studies employed a thematic analysis (Burke, 2019).

The most explicated qualitative inquiries into the use of DMT over the last twenty years have concentrated on two themes. That of the experience of taking a single DMT agent (*see* Miller

& Jezewski, 2006; Miller et al., 2012) and the use of various DMT agents (*see* van Capelle et al., 2017; van Reenen et al., 2019). While in no way minimizing the value of single DMT agent studies, questions can be raised as to whether such findings are applicable to PwRRMS who use alternative agents of DMT. Yet another crucial question, one that has received even less attention in the literature, concerns the experience of using different forms of DMT (i.e., capsule, infusion, and/or subcutaneous injection). The prominence of the work by van Capelle et al. (2017) and van Reenen et al. (2019) has cast a light on this phenomenon in terms of understanding the experience as not purely rational and individual. However, a closer look at the ways in which these contributions enhance the body of knowledge reveals inherent tensions. Some of this tension arises from the recruitment material employed by van Reenen et al. (2019). Further complicating matters, was individuality. Furthermore, alterations in DMT regimen and the unpredictable nature of RRMS meant drawing conclusions from these studies could be troublesome. Nonetheless, there is little doubt that contemporary research is required to reflect developments in theoretical knowledge.

To summarise, it is apparent that there is a need for a study into the experience of being diagnosed with RRMS and the experience of taking DMT. The study would aim to embrace the complexity of both illness and treatment, whilst seeking to analyse RRMS as a phenomenon of experience. By opening up the experience in this way, and introducing an alternative framework of researching, the study would aim to overcome the limitations of previous research and fill gaps in the body of knowledge.

2.6 Relevance to the practice of Counselling Psychology

According to the BPS (2017), a cornerstone of the counselling psychology profession is the emphasis placed on the subjective experience of the individual. This thesis attempts to align itself to this principle, and to the others underpinned by the profession, by moving away from ill-fitting paradigms of much of the research of the last 20 years, and toward a concern for individual experiences and the meanings of those experiences. It is envisaged that the conclusions drawn from this thesis will prompt discussions surrounding the subjectivity of the individual, which once taken into consideration could lead to revisions and developments in clinical practice. At the same time, this thesis aims to contribute to the professional division by broadening the body of knowledge pertaining to autoimmune diseases, which up to now is largely dominated by quantitative inquiry.

For some time now, there has been a call for an integration of counselling psychology and neuropsychology (Goss, 2015a; 2015b; Rizq, 2007). This thesis aspires to respond to this call by respecting scientific exploration of RRMS but firmly positing that this phenomenon should not be seen as a singular concept which exists independently. By developing this stance, this thesis seeks to encourage counselling psychologists interested in the uniqueness of subjective experiences to embark on clinical experience and research in what is currently a largely scientific arena, whilst remaining congruent to the profession's commitment to the 'scientist-practitioner' model (BPS, 2017).

2.7 Aim of Research

The focus of this thesis is the lived experience of being diagnosed with RRMS and the lived experience of taking DMT. The aim is to offer a contribution to the body of knowledge by answering the question of whether the current theories and studies are representative of PwRRMS. The attempt at answering this question is not necessarily a new phenomenon. Throughout its history, an abundance of literature has been characterized by innovation and limitation, progression and regression. Whilst researchers have continually reworked their methods in light of new developments, the contemporary change in research angle in this thesis is purposeful. It is believed that this line of inquiry will contribute findings surrounding the subjectivity of the individual which once taken into consideration could lead to revisions in clinical practice and in the packages of care for PwRRMS.

2.8 Research Questions

The research questions for this thesis were as follow:

x] How do individual's experience a diagnosis of RRMS?

And

x] How do PwRRMS experience taking DMT?

Chapter Three

Methodology

This chapter introduces and substantiates the adopted methodology and method. Methodology differs from method in that the former relates to an approach to investigating whilst the latter relates to technique (Silverman, 2011). Willig (2008) suggests the eventual choice of methodology will be directly primed by the ontological and epistemological framework adopted by the researcher. For that reason, this chapter emphasizes and reinforces the embodied ontology and epistemology. More specifically, a rationale for selecting a hermeneutic interpretative phenomenological method against a backdrop of alternatives is presented. Next, the specifics of the data collection process are attended to, namely, sampling, the inclusion criteria, recruitment, participants, and the interview procedure. The chapter is also driven by the need to make clear the process of conducting a data analysis. That is, transcription, the analysis process, and the relevance of trustworthiness, validity, and rigour. Following a declaration of the ethical considerations taken into account, the chapter concludes with a discussion on reflexivity.

3.1 Ontology and Epistemology

Ontology and epistemology are often contested. “Ontology ‘relates to the nature of the social and political world’ and epistemology ‘to what we can know about it’, [so] ontology is logically prior in the sense that the ‘it’ in the second term [the definition of epistemology] is, and can only be, specified by the first [the definition of ontology]” (Hay, 2007a, p.117). Dixon and

Jones (1998) disagree. They argue ontology is grounded in epistemology. Alternatively stated, ontology invariably rests upon epistemological priors which permit assertions relating to the structure of the real world. Spencer (2000) critiques this line of reasoning on the grounds that escaping a theory of ontology is unattainable. Thus, the question is whether or not ontology is consciously acknowledged and deliberated or whether ontology is left as an implicit presupposition of epistemology.

It would be wrong to suppose that the search for an uncontentious manner in which to resolve this contestation is a straightforward endeavour. However, as an alternative and whilst recognizing the complexity of this endeavour, a framework that is understood and used consistently should be made available by researchers (Willig, 2008). The framework would set out clearly the relationship between what can be studied (ontology) and how can we know (epistemology). To say that there is no way of promoting one collection of beliefs over another means that the framework made available highlights the held position rather than the position being of more significance than another (Morrow et al. 2012; Ponterotto, 2005).

3.2 Ontological Framework

Ontology, originating from the Greek *ónto* meaning *being* and *lógos* meaning *word or study*, places inquiry onto the “nature of existence, or being” (Mills, et al., 2009, p.630). In Heidegger’s (1962) writing, human beings are permanently participating in the context of life. Therefore, ontology is the study of the mode of *being in the world* which is understood as the tactile things of the world that human beings inhabit (Heidegger, 1962). With this conceptualisation in mind, positions on the ontological spectrum, namely, *naïve realism, critical realism,* and *relativism* (Ponterotto, 2005) are now explored.

3.2.1 Naïve Realism

> "We all start from "naive realism," i.e., the doctrine that things are what they seem. We think that grass is green, that stones are hard, and that snow is cold. But physics assures us that the greenness of grass, the hardness of stones, and the coldness of snow are not the greenness of grass, the hardness of stones, and the coldness of snow that we know in our own experience, but something very different." (Russell, 1962, p.13)

Naïve realism (also known as *positivism)*, according to Ponterotto (2005), theorises an observable and measurable reality to exist independent of human existence. Interestingly, the label '*naïve*' appears to disparage and devalue the position even if one was to subscribe to the associated assumptions about knowledge production (Willig, 2012). Pring (2004) suggests a reason for adopting this position "might be to predict what will happen in the future or what would happen if there were to be certain interventions" (p.62). Naturally, criticism can be attributed to this position. For instance, the application of universal causal links established in the study of natural sciences can be difficult to replicate in the social sciences as individuals can have multiple perspectives and interpretations of events. Consequently, an absolute truth can be difficult if not impossible to determine. In response, Karl Popper suggests the valuable qualities of the scientific method should not be disregarded. Popper in *the Logic of Scientific Discovery* (1959) proclaims no absolute truth exists and that scientific theory cannot be confirmed, only falsified. But, of course, in the event that theory does not obtain the absolute truth and rather becomes closer to the truth, an assumption remains that theory is objective and reflective of reality. Despite Popper's (1959) rebuttal in relation to this discussion, *naïve realism* was deemed incompatible with the aim of this thesis. Applying a methodology conventionally adopted within the natural sciences into the social sciences being the point of divergence.

3.2.2 Critical Realism

> “All theories about the world are seen as grounded in a particular perspective and worldview, and all knowledge is partial, incomplete, and fallible.” (Maxwell, 2012, p.5)

Critical realism (also known as *post-positivism),* located between *naïve realism* and *relativism* (Sayer, 2000), takes a step beyond *naïve realism* by accepting a reality to exist but “recognises that there are enduring structures and generative mechanisms underlying and producing observable phenomena and events” (Bhaskar, 1989, p.2). Subsequently, reality can only be known imperfectly through subjectivity, construction and interpretation. Two key criticisms have been attributed to *critical realism*. Firstly, the case can be made that what is presented and, therefore, talked about as extra-discursive can in fact be analysed from a *relativism* perspective. In other words, *critical realism* can be understood as a discursive endeavour meaning that material practices can be reduced to discursive practices (Edwards et al., 1995). Secondly, Sims-Schouten et al. (2007) make the argument that *critical realism* has no systematic method of distinguishing between discursive and non-discursive. Therefore, the construction of factors as one and not the other comes down to individual preference. That is, a preference guided by a researcher’s framework (Sims-Schouten et al., 2007). With these two criticisms in mind and as was with the case of *naïve realism*, *critical realism* was deemed incompatible with the aim of this thesis.

3.2.3 Relativism

> "It is not that texts are more real, more singularly described than the rest of the world; bur rather, that the rest of the world is like text. It is *all* represented and interpreted." (Edwards et al., 1995, p.32)

Relativism (also known as *constructivist–interpretivism*) supposes there to be multiple, constructed versions of reality as opposed to a single reality (Ponterotto, 2005). If reality is influenced by the context of the situation, it should be known that this extends to individual experience and perception, the social environment and the interaction. Guba (1990) takes this one step further and indicates towards multiple interpretations of reality, locally and historically exclusive and incapable of being classified as correct or false. Ultimately, *relativism* presents conclusions which cannot be known for definite as none of the multiple realities have precedence over the other in terms of claims to represent the truth. This extension of *relativism* has invited criticism. For instance, Bernstein (1983) argues *relativism* is anti-foundational as we float in an unbound world in which all are limited to a clash of opinion. Furthermore, Parker (1999) suggests "different realities can never be rationally assessed, and freedom of opinion is rendered equivalent to toleration of anything being said" (p.66-67). However, Edwards et al. (1995) suggest these criticisms are incorrect. In reference to "anything being said", Edwards et al. (1995) state that this statement "is a variant of realism, suggesting merely a different arrangement of cogs in the underlying generative mechanism; relativists make assumptions about the world, but they also hold those assumptions to be permanently open to examination and critique" (p.81). With this argument in mind and the overall underpinning of the position, the corresponding ontology of this thesis was *relativism*.

3.3 Epistemological Framework

Responding to the epistemological question, namely, *how we can know* requires consideration of the nature of the relationship between the knower and what can be known (Lincoln & Guba, 1985). A method in which to access these assumptions is to ask a "series of questions such as: what kind of knowledge do I aim to create? What are the assumptions that I make about the world that I study? How do I conceptualize the role of the researcher in the research process?" (Willig, 2012, p.10). To arrive at an epistemological position, Willig's (2012) conceptualisation is employed.

3.3.1 Realism

> "To what degree can I trust the reporter that the research is true? To what degree can I believe that all possible occurrences of error were minimised rather than 'built into' the design?" (Brink, 1991, p.165)

The *realist* position aims to capture and present an accurate and truthful account of what is occurring in the 'known world'. The 'known world' is thought to exist independently of the researcher and the research participant and is underpinned by the premise that there exists "processes and/or patterns of a social and/or psychological nature which characterise and/or shape the behaviour and/or the thinking of research participants, and that these can be identified and conveyed by the researcher" (Willig, 2012, p.15). Furthermore, the researcher is thought to be capable of investigating the 'known world' without bias and influence and vice versa (Ponterotto, 2005). According to Willig (2012), the *realist* position can be divided into a *naïve* or a more *critical* distinction. The *naïve realist* position proclaims an associated theory of truth in which there is a knowable and direct relationship between what presents itself and what it represents. The *critical realist* position varies from the *naïve* position in that the *former* is based on the assumption that although data can be informative of the ‘known world’, this data is unable to do so in a self-evident, unmediated manner. Alternatively put, the *critical realist* position requires data to be interpretated in order for the underlying structures to be accessed. The question then needs to be asked if either of these two distinctions are compatible for the purposes of this thesis. The answer was no, with the reasons as follow. Firstly, the position can neglect and/or diminish the interpretive potential of the data by taking research participant accounts at a certain value as opposed to considering the contextual and symbolic meaning and function. Secondly, although not always the case, conclusions can be derived that are unable to be justified using qualitative methods.

3.3.2 Social Constructionism

> “In order to account for the thing(s) you find yourself and other people doing … you have to come up with the idea that people have a thing called personality that is responsible for this behaviour.” (Burr, 2003, p.21)

Peter Berger and Thomas Luckmann’s influential book *The Social Construction of Reality: A Treatise in the Sociology of Knowledge* (1966) suggests the ‘known world’ is socially defined. Similarly, Kelly (2008) suggests the ‘known world’ is “an invention or artefact of a particular culture or society” (p.21). A question required to be asked is what does this mean for research and researchers. According to Berger and Luckmann (1966), researchers should abandon aspirations to gain insight into the inner experience of the research participant and/or how sense is made of experience in favour of understanding how research participants construct versions of the ‘known world’ depending upon their social context.

The *social constructionist* position can be labelled *relativist* (Willig, 2012). The label can be assigned on the grounds that brought into question is the ‘out-there-ness’ of the ‘known world’ and discarded is the notion that “objects, events and even experiences precede and inform our descriptions of them” (Willig, 2012, p.26). Thus, the *social constructionist* position as *relativist* conceptualises experience as “socially manufactured through human interaction and language” (Houston, 2001, p.846). In other words, contextual, linguistic, and relational factors combine to construct the ‘known world’ rather than the ‘known world’ determining how it is described or talked about. It remains important to remember that not all *social constructionist* researchers would label themselves as *relativists* (Schwandt, 2003). *Radical constructionists* break with convention and develop a theory in which knowledge does not reflect an ‘objective’ ontological reality, but exclusively an ordering and organization of a world constituted by a socially negotiated meaning. Although, advocates have different conceptualisations of this argument depending upon the ontological framework adopted, the assumption remains that the ‘known world’, no matter how it is defined, is subjective, and the thinking subject has no alternative but to construct what he or she knows on the basis of his or her own experience. In contrast, the *moderate constructionists* go beyond “the study of localised deployments of discursive resources and make connections between the discourses which are used within a particular local context and the wider socio-cultural context” (Willig, 2012, p.28). A difference between the *radical* and *moderate constructionist* position is that the former position is *relativist* in which there is ‘nothing outside the text’; whereas the later, believes that social constructions take place in a material world of bodies, objects, politics and economics (Hammersley, 1992). Having mapped out three *social constructionist* positions, a decision was made to opt against an implicit *social constructionist* position for the purposes of this thesis.

3.3.3 Phenomenology

> "Human beings, who are almost unique in having the ability to learn from the experience of others, are also remarkable for their apparent disinclination to do so."
> Douglas Adams (1991, p.188).

Etymologically, Friedrichsen and Burchfirld (1996) state phenomenology originates from two Greek terms *phainómenon* and *lógos*. *Phainómenon,* meaning *that which appears,* and which can be traced back to the Indo-European root *pha* connected with the idea of light or clarity, and *lógos,* meaning *word or to study*. In his text *Being and Time* (1962), Heidegger clarifies his conceptualisation of the term phenomenology. He suggests *phenomenon* means "that which shows itself in itself" (1962, p.51) and *logos* meaning "lets something be seen" (1962, p.56).

> "Phenomenology means: to let what shows itself be seen from itself, just as it shows itself from itself. That is the formal meaning of the type of research that calls itself "phenomenology." But this expresses nothing other than the maxim formulated above: "To the things themselves!" (Heidegger, 1962, p.32)

The epistemological underpinnings of phenomenology can be separated into *analytical* and *continental*. The former places emphasis on objectivity in terms of logic and reason and strives to verify truth and untruth. Meanwhile, the latter typically considers relationships "to be 'parts of the larger unities' and as properly understood and dealt with only when fitted into those unities" (Prado, 2003, p.10). The *continental* underpinning can be further separated into two branches: *transcendental* and *existential*. The point of divergence pertaining to the notion of the epoché. That is, epoché supposes the possibility of performing a suspension of the natural attitude toward the world.

Edmund Husserl, widely considered to be the intellectual founder of *transcendental phenomenology*, presented the epoché as an essential method for the practice of phenomenology. He said:

> "How does it become possible, thanks to the epoché, this subjectivity in its accomplishment, in its transcendental "conscious life," extending into hidden subsoils, in the distinct manners in which it "brings about," within itself, the world as ontic meaning." (1983, p.153)

This conceptualisation of the epoché was revisited and reworked until Husserl published *The Crisis of the European Sciences and Transcendental Phenomenology* (1936). There he describes the epoché as a method of phenomenological suspension of all naïve prejudices that have the givenness of the natural attitude. It extended to the suspension of all the elements of experience, so that phenomena can be seen as they really are. Phenomenological epoché represented a gravitation toward the essential structures of experiences or a construction of the world as it is when all judgements are suspended.

> "We place in brackets whatever it includes respecting the nature of being: this entire natural world therefore which is continually "therefore us", "present to our hand", and will ever remain there, is a "fact-world" of which we continue to be conscious, even though it pleases us to put it in bracket" (Husserl, 1970, p.110).

Whilst Husserl argued that by the use of the phenomenological epoché individuals could distance themselves objectively from that which was to be phenomenologically investigated, future philosophers disagreed. For instance, the *existential* branch of Martin Heidegger (1889-1976) broke away from *transcendental* phenomenology due to this point of divergence. Although Heidegger's description of the epoché appeared to remain tied to Husserl's original conceptualisation, Heidegger (1962) changed the focus of attention from the invariant meaning of something to the mode of being of something. This point of divergence fashioned *descriptive phenomenology* and *interpretive* phenomenology. *Descriptive* phenomenology suggests "the impact of the researcher on the inquiry is constantly assessed and biases and preconceptions neutralized, so that they do not influence the object of study" (Lopez & Willis, 2004, p.14). By contrast, *interpretive* phenomenology viewed description and interpretation as inextricably linked. Analysing parts of phenomena required the phenomena to be appreciated in conjunction to the whole and vice versa. This circulatory process referred to as the hermeneutic circle suggests each and every element (may it be a word, an action, an experience) has its meaning only in a certain context, in a certain connection to which it belongs as a part of this whole. The meaning of the whole depended on the meaning of the single things as its parts. Thus, hermeneutics is founded on change. That is, as the world is in constant change, so are individuals, and subsequently, their interpretations.

To further understand *interpretive* phenomenology, Heidegger (1962) proposed individuals are born and embedded into the context of the world and it is how they interpret the world which determines the way they are affected by it. If the world is in this constant interpretative state, then individuals create themselves through this interpretation. Therefore, for Heidegger (1962), the focus is not on studying the essence but rather studying the experience of being in the world, whereby contextual underlying meanings are obtained and valued through interpretation

(Gearing, 2004). Heidegger (1962) emphasised this point by adopting the German term '*dasein*'. *Da* meaning *there and sein* meaning *being*. *Dasein* is a unified concept meaning that it cannot be viewed separately and independently of the world. According to Heidegger (1962), the central question of what it meant *to be* was a question in which *being* preceded an explanation of *why*, primordial in this sense. Heidegger (1962) opposed the traditional ontology as this central question of *being* was sidestepped. He referred to this ontology as a 'substance ontology'. Although Heidegger (1962) argued that this 'substance ontology' was the most prevalent mode of perceiving and experiencing the world, he maintained that substances are not reducible to self-sufficient, independent entities.

To summarise, various points of divergence have been posited, each growing from a particular view and assumption about the epoché. Specifically, this thesis aligns with *interpretative phenomenology* in that it moves away from acquiring an understanding of the world by simply determining elements. Instead, if truth was found to exist, experiencing it would be felt in a kind of being-ness and would be a result of a thing being understood as it was meant to be as opposed to an object corresponding accurately with a mental representation. With that said, given the importance of remaining consistent when selecting a method of inquiry, the question of "how can the inquirer go about finding out what he or she believes can be known" (Guba & Lincoln, 1994, p.108) will be explored next.

3.4 Methods

3.4.1 Qualitative Research Methods

Various methods of performing qualitative research are available. According to Willig (2008), the decision to give preference to one method over another stems from a researcher's line of inquiry. This line of inquiry should inform the method selected as each method will seek to understand a different layer of experience (Willig, 2008). The following research methods were considered during the design process but were dismissed with the rationale for doing so now explained.

3.4.1.1 Grounded Theory

Strauss and Corbin (1998) suggest Grounded Theory (GT) aims to achieve 'saturation' - a position in which no additional themes emerge but existing themes are developed in order to account for known instances of a phenomena. Often the argument is held that GT is better suited to instances in which there is a concentration on social processes that account for phenomena, rather than being a method striving to obtain an understanding of individual experiences (Willig, 2008). With this in mind, adopting a GT approach was deemed to be counterintuitive to the objectives of this thesis.

3.4.1.2 Discourse Analysis

Broadly speaking, Discourse Analysis (DA) places focus on how individuals adopt language to construct and impose on a societal level (Burman & Parker, 1993). DA begins with the premise that not only is language an active agent applied to mediate but language provides a position and structure through which individuals are mediated (Willig, 2008). In other words, DA moves beyond content and examines orientation (i.e., how language can aid in negotiating phenomena). Due to this emphasis placed on the function of language and social processes, DA was ruled out as an appropriate method for this inquiry.

3.4.1.3 Thematic Analysis

According to Howitt and Cramer (2008), Thematic Analysis (TA) places an emphasis on the identification of themes and patterns of behavior. This process of identifying themes involves the coding of data. Coding and theme development in this way places a focus on outlining meaning across a whole data set. With this in mind, TA was ruled out as a method as it is often better suited to greater samples, or in the event that the research aim, and objectives do not require a deeper sense of meaning to be made of individuals' and their experiences (Smith, 2010).

3.4.2 Hermeneutic Interpretive Phenomenology

Max van Manen followed the phenomenological tradition by reflecting the existential legacy. He said:

> "as we research the possible meaning structures of our lived experiences, we come to a fuller grasp of what it means to be in the world as a man, a woman, a child, taking into account the sociocultural and the historical traditions which have given meaning to our ways of being in the world" (1984, p.38).

He writes further:

> "phenomenology does not offer us the possibility of effective theory with which we can now explain and/or control the world but rather it offers us the possibility of plausible insight which brings us in more direct contact with the world" (1984, p.38).

Phenomenology in this sense attempts to trace and uncover variations of experience through visiting and revisiting the phenomenon to expose that which lays just behind it in a process of revelation (van Manen, 1990). Specifically, the heuristic approach formulated by van Manen (1990) advocates engaging with the data to allow the phenomenon to come to light in a specific way which opposes the adherence of a set of rules or techniques (Earle, 2010; Ihde, 1986; van Manen, 1990). Furthermore, this heuristic approach includes interpretation which Willig and Bellin (2012) conceptualise as:

> "a movement from presupposition to interpretation and back again, whereby the researchers' presuppositions (e.g., about the meaning of a word or the significance of an expression) are tested in the light of an evolving meaning of the account he or she is trying to understand and make sense of. This process has been referred to as the hermeneutic circle." (p.117-118).

This process described as interpretive and engaging with the phenomenon through a reciprocal process of dialogue with the individual is integral to the hermeneutic interpretive phenomenological method. With this in mind, not only does this process align with the corresponding ontology of this thesis but also the aim and objectives. The question is then how hermeneutic interpretive phenomenology should be implemented. The answer is a simple one. There is no method (van Manen, 1990). But, of course, van Manen, (1990) did pose the following steps which form the procedural organising structure:

> "(1) turning to a phenomenon which seriously interests us and commits us to the world.
> (2) investigating experience as we live it rather than as we conceptualise it.
> (3) reflecting on the essential themes which characterise the phenomenon.
> (4) describing the phenomenon through the art of writing and rewriting.
> (5) maintaining a strong and oriented pedagogical relation to the phenomenon.
> (6) balancing the research context by considering parts and whole" (p.30-31).

Following an explanation of the data collection procedure, an account of how van Manen's method was interpreted and operationalized is provided.

3.5 Procedure: Data Collection

3.5.1 Sampling

The following describes the composition of the participant sample and the recruitment procedures.

3.5.2 Inclusion Criteria

Eligible participants satisfied the following criteria: either gender; aged eighteen or above; a diagnosis of RRMS according to the McDonald Criteria of 2017; and to have taken a DMT agent either in capsule, infusion, and/or injection form. Applicable DMT agents included but not limited to: Alemtuzumab (Lemtrada®); Natalizumab (Tysabri®); Ocrelizumab (Ocrevus®); Dimethyl Fumarate (Tecfidera®); Fingolimod (Gilenya®); Glatiramer Acetate (Copaxone®); Ocrelizumab (Ocrevus®); and/or Peginterferon Beta-1a (Plegridy®). Those who experienced active suicidal ideations and/or required an interpreter were not eligible for inclusion.

3.5.3 Recruitment

A Recruitment Poster (*see* Appendix 1) pertaining to the research, the inclusion criteria, and the researcher's contact details was advertised via; noticeboards at local Community Centres (i.e., physical centres); Social Media platforms (i.e., Facebook, Twitter, and Instagram); and through user forums available via the National MS Society. Individuals' wishing to take part in the study contacted the researcher directly via email or telephone. Following an agreement of meeting the inclusion criteria and providing an initial consent to participate, a research interview was scheduled and agreed at a convenient time for both parties. All interviews were undertaken between October and November 2019 via an online platform, namely, Skype.

3.5.4 Participants

Six participants (*see* Table 3.) were recruited from across England for this study. In order to preserve confidentiality and anonymity (*see* 3.10 Ethics), pseudonyms were utilized and detail intentionally restricted.

Table 3. Participants' Profile

	Ethnicity	**Age**	**Occupation**	**Symptom Onset**	**Diagnosed**	**Disease Modifying Treatment**
'Sonal'	British - Asian	18 - 35	Unemployed	2011	2014	Dimethyl Fumarate
'Naira'	British - Arab	18 - 35	Psychological Therapist	2004	2014	Alemtuzumab
'Faustina'	Spanish	55 +	Retired	1998	2004	Peginterferon Beta-1a
'Savannah'	British	18 - 35	Banking Manager	Early 20's	Early 20's	Dimethyl Fumarate
'Alexandra'	Greek Cypriot	18 - 35	Probation Officer	2015	2018	Alemtuzumab
'Audrey'	Black - British	18 - 35	Self - Employed	2010	2012	Ocrelizumab

3.5.5 Interview Procedure

In preparation for the data collection phase, pilot interviews were conducted so that an ability to ask open-ended questions whilst building rapport, gaining trust, and exploring different aspects of the phenomena could be developed. According to Kvale and Brinkmann (2009), pilot interviews enable plans to be put in place for difficulties should they arise. With this in mind, two pilot interviews with non-participants were undertaken. These interviews resulted in the development of possible probes and prompts to facilitate elaboration (discussed below) and participants having an opportunity to provide feedback on the interview platform, namely, Skype, which was deemed to be suitable.

Before the interview commenced, participants were presented with a Participant Information Sheet (*see* Appendix 2). Given that an interview of this kind may be regarded as a co-determined interaction, Kvale and Brinkmann (2009) suggest creating and employing an interview schedule. An interview schedule, designed to guide rather than dictate, for an articulated adult should last between forty-five to ninety minutes in duration and contain between six and ten open questions along with prompts (Kvale & Brinkmann, 2009). In corroboration with commonly associated symptoms of RRMS (*see* 1.1.2 Pathophysiology, Symptoms and Classifications), a flexible interview schedule with economically selected open-ended questions was adopted (Paterson & Scott-Findlay, 2002). At the interview, participants were provided with an opportunity to ask questions about their involvement in the study after which they were presented with the Informed Consent (*see* Appendix 3). The Informed Consent explained how information derived from participation would be disseminated and stored. Each participant was provided with; (i) details of the researcher's position; (ii) an explanation of the aim of the research and interview; and (iii) a detailed description of the confidentiality protocol. Participants were encouraged to abstain from disclosing information in the interview, which could lead to the identification of a third party. In the event they needed to make reference to a third party, they were asked to adopt a pseudonym. At this point, participants were again encouraged to ask questions and then invited to sign the Participant Information Sheet and the Informed Consent. Data collected from each participant pertained to information relevant to the inclusion criteria, as well as information relating to the participants' profile (*see* 3.5.4

Participants). With consent, audio recording of the interview began. Interviews, all of which were audio-recorded, contained up-to seven openly phrased questions. Each participant was allowed time to provide full answers and in the event that this was not possible the use of probes and prompts facilitated this process. For example, all participants were posed the question: *can you tell me about your experience using DMT?* The probes and prompts were as follows; *can you describe your experience of using DMT. What things could you do before and/or after DMT? Can you tell me anything about your experience that has been successful and/or difficult?* The effect of the questioning on the participant was continuously monitored throughout the interview process by remaining vigilant to deviations in participant non-verbal behaviour. None of the participants presented with discomfort during or after the interview. Following the completion of the questioning, participants were provided an opportunity to deliberate and reflect on the process and invited to ask questions. Additionally, participants were debriefed with the assistance of the Debrief Information Sheet (*see* Appendix 4) and encouraged to make use of the contact details of the external agencies provided as a result of their participation, if required.

3.6 Procedure: Data Analysis

3.6.1 Analysis Process

The analysis process reflected an interpretation of van Manen's (1990) framework which meant incorporating four reflective methods: immersion into the lived experience, composing textual portrayal, phenomenological thematization, and reflective writing. Immersion into the lived experiences was facilitated by listening to the audio files and reading the transcripts. Immediately, the urge to do something was contained, as was suspending understanding. Receptivity was the position sought. Having read and listened to the transcripts as a whole, each transcript was read again. This time with a focus on each sentence, line-by-line. Van

Manen (1990) termed this the ‘selective reading approach’ whereby thoughts, questions, and comments related to RRMS and DMT are marked in the margin to capture pre-understanding. Here, pre-understanding is in reference to the already held understanding of the phenomena and includes, among others, presuppositions, traditions, expectations and hopes in relation to the research (outcome). Next, composing textual portrayals meant identifying experience-based descriptions that would form the foundation of the analysis. A textual portrayal referred to a fragment of text that described elements of the experience in language that spoke to the readers imagination and provided insight into the phenomena. In commenting on this process, it should be noted that the textual portrayals did not necessarily follow each other chronologically in the transcript. And so, at times the content structure was changed in an attempt to construct a more evocative phenomenological narrative. The textual portrayals reflected the phenomenological thematization (i.e., structures of the meaning of the experiences). To that end, and for purposes of clarity and coherence, the phenomenological themes were arranged in accordance with existential life worlds (van Manen, 1990). That is, corporeality, relationality, spatiality, and temporality (van Manen, 1990). The themes were finalized by means of reflective writing.

3.6.2 Trustworthiness, Validity and Rigour

As Finlay (2008) argues, trustworthiness, validity and rigour are key components to qualitative research. This is very much consistent with the criteria that can be used to assess such components, namely, “sensitivity to context, commitment and rigor, transparency and coherence, and impact and importance” (Yardley, 2000, p.180-183). The first dimension (i.e., sensitivity to context) can be established through multiple means. For instance, sensitivity to the relevant theoretical literature, the sociocultural context, and/or the participants’ perspectives. In the context of this thesis, sensitivity was demonstrated through the selection of the hermeneutic interpretative phenomenological method as a means of honouring the experience of each participant and through promoting a respect for the quality of data emerging. Maintaining such sensitivity throughout the interview process is integral as Stern (1985) argues "there can be no fixed criteria for establishing truth and knowledge, since to limit the criteria for truth would mean restricting the possibilities for knowledge" (p.217). In a related vein, the second dimension (i.e., commitment and rigour), is suggestive of the need for an extended engagement with the research study, methodological competency, immersion into the data, and a demonstration of delving beyond the descriptive account into a detailed analysis (*see* 3.6.1 Analysis Process). According to Yardley (2000), the third dimension (i.e., transparency and coherence), "describes the "fit" between the research question and the philosophical perspective adopted, and the method of investigation and analysis undertaken" (p.222). Various endeavours were undertaken to underline the clarity of the proposed argument and transparency of methods. For example, the development of the interview schedule was responsive to the input from both the pilot interview participants and the research director of studies. The realm of the fourth dimension (i.e., impact and importance), emphasises the manner in which study results can be applied theoretically, socio-culturally, and practically. For Yardley (2000), "there are many varieties of usefulness, and the ultimate value of a piece of research can only be assessed in relation to the objectives of the analysis, the applications it was intended for, and the community for whom the findings were deemed relevant" (p.223). In the context of this thesis, an alternative theoretical method of understanding the experiences of being diagnosed with RRMS and taking DMT was proposed. Not only is it envisaged that this may provide an original contribution to the body of knowledge pertaining to RRMS and DMT, but the thesis offers a methodological perspective as to how a phenomenological approach may be applied to future research in the field.

3.7 Ethical Considerations

Ethical approval from the University of East London's (UEL) School of Psychology Research Ethics Sub-Committee was sought and gained prior to the commencement of participant recruitment (*see* Appendix 5). In addition, the policies and practices set out in the British Psychological Society (BPS) 'Code of Human Research Ethics' (BPS, 2014) and the UEL's 'Code of Practice for Research Ethics' (UEL, 2015) were maintained throughout the research process.

3.7.1 Defining Ethics

The BPS in the Code of Human Research Ethics refer to research ethics as "the moral principles guiding research from its inception through to completion and publication of results" (2014, p.5). Given the dynamic nature of ethical research practice which involves monitoring throughout the course of research and the nature of phenomenological studies aiming to enter the 'lifeworld' of participants, a duty of care was placed on ensuring the physical and emotional safety of participants. In corroboration with the ethical principle of 'respect for the autonomy and dignity of persons' (BPS, 2014), although the research study did not anticipate causing distress to any participant, in the event of distress being experienced, participants were verbally reminded of their voluntary participation and their right to withdraw. A subsequent decision to withdraw would be respected.

3.7.2 Informed Consent

In addition to the Informed Consent (*see* Appendix 3), the principles outlined by the BPS (2014), namely, responsibility relating to the avoidance of harm, and integrating and embodying honesty, accuracy, clarity, and fairness were adhered to. The principle of responsibility was adhered to in various ways. For instance, participants were informed that they were under no obligation to take part in the research and research interview. Should they wish to take part, they were at complete liberty to withdraw at any time. Although no participant took up this option to do so, had they done so, any data provided would have been destroyed. Furthermore, participants were provided with an option to withdraw their informed consent up to three weeks after the interview by advising the researcher of their decision. In relation to integrating and embodying honesty, accuracy, clarity, and fairness, the informed consent, audio recordings, electronic interview transcripts and researcher notes were all stored separately in a secured location in accordance with the Data Protection Act 1998. The material was only available to the researcher, potentially the research director of studies, and the research examiners at their request. All the material would be destroyed one year after the thesis had been marked and the results ratified. Finally, participants were notified that the research would contribute toward a thesis, which would be assessed and may potentially be published. In the event of any publication, participants were informed that their name would not appear and the likelihood of verbatim, but anonymised extracts being included.

3.7.3 Debriefing

Participants were presented with a Debrief Information Sheet. The purpose of which was to notify participants' of: (i) the nature of the research; (ii) the confidentiality protocol; (iii) their right to withdraw their consent to have their interview material included in the research (in the event a participant wished to do so they were required to inform the researcher of their decision within a three-week period starting from the time of the interview); and (iv) suggested support services that are available should the participant require them as a result of their participation in the study. In the event of adverse experiences to the researcher, these would be discussed with the researcher's director of studies.

3.7.4 Confidentiality

The procedural steps intended to preserve anonymity and confidentiality were discussed with each participant in line with the Participant Information Sheet. In respecting such confidentiality, a pseudonym was assigned to each participant and any identifying information was intentionally removed. In addition, all consent forms were stored securely and separately from the audio recordings and transcribed materials. The sole responsibility for this data was held by the researcher.

3.8 Reflexivity

Malterud (2001) defined reflexivity as a "researcher's background, worldview, and position will shape what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, and the findings considered most appropriate" (p.483-484). Meanwhile, Alase (2017) suggested that "it is very important that a thick [and thoughtful] personal reflective description be included in the narrative of the research study, so that the audience can see for themselves the journey that the research study has gone through" (p.146-149). By accepting these two statements, the question of how to facilitate this process emerges. Willig (2008) emphasised personal and epistemological reflexivity to guide this process.

According to Fook and Gardner (2007) personal reflexivity can be regarded as an ability to discern that all elements of the researcher and their context influences the way they research. This can require an exploration of areas such as power, inequality, gender in addition to discerning how assumptions, values, emotions and so forth can influence the research process (Finlay & Evans, 2009). By pursuing this line of inquiry, questions naturally arise. Can a researcher suspend their judgement(s) in the research process? Who is a researcher in front of the research participant? Would becoming all accepting and understanding render a researcher artificial? In doing so, would this reflect reality? Or rather, reinforce a power differential, perceived or otherwise. By adopting a reflexive attitude in acknowledging the possible impact of personal factors on the research process, an attempt (as far as reasonably possible) was sought to minimise the challenges and difficulties in conducting research. Firstly, identifying as a British-Asian researcher meant commonality with one of the six research participants. What was striking was the way 'Sonal' at times alluded to this unity. For example, in her account, as she talked about the importance of marriage in the culture in a condensed and skipping style, this concept was well understood. As was how the prospect of marriage would be difficult for her due to the moral fortitude, and the commitment to the principles of the culture. Equally, the buoyancy of spirit in which she made inferences to her conceptualisation of the cycle of life (i.e., birth, death, and rebirth through which the soul crosses from one life to another) yielded further familiarity. Secondly, undertaking clinical placements at two different neurological services may have made it easier for the recruited participants to be interviewed about their experiences since both parties were familiar and versed in the phenomena. Here, it may be helpful to be reminded of the words of Langdridge (2007) who argued that being contextually sensitive, and selecting a suitable methodology embedded in sound reflexive orientation, demonstrates trueness to the theoretical underpinnings of phenomenological inquiry.

Epistemological reflexivity can refer to what is anticipated to be captured by the research, the assumptions made throughout the research process, and the influence of this on the research results. To begin with, it must be acknowledged that the desire to embark on this research stems from the requirements of the Professional Doctorate in Counselling Psychology. In addition to fulfilling the assessment criteria of this programme of study, the motivation to engage in this particular area of research stemmed from two further factors. Firstly, an influencing motivation is a piece of work undertaken with a service user at a previous employment endeavour. The service user in question had presented to an Improving Access to Psychological Therapies service with a diagnosis of MS. As an employment advisor, the purpose of my role was to support the service user back into sustainable employment. What was enriching and captivating about the work with this service user was not only how the work sparked an interest in MS but how the working relationship cultivated an interest in psychoanalysis and later, an understanding of psychoanalytical concepts. For instance, at the initial appointment, a role was immediately inscribed in that I was required to 'do' something to the service user. In other words, I was required to utilise specialist knowledge in order to ground the nature of the service user's diagnosis, and that specific interventions would be applied in the social norms to which if the service user followed would ameliorate or remove the barriers ascribed to his disabling symptoms. On recollection, internal questions emerged which were as follow: what do nosological designations refer to? What will influence that choice of name? What are the effects? Is it possible to work with a designation without having a previous understanding of it? And what is the relationship between these designations and the work of an employment advisor? Unable to answer any of these questions at the time, I experienced myself as fragile. That is, I experienced a tension between helplessness and a desire to empower. To further complicate matters was the evolving relational pattern that had begun to emerge in the sessions. As the service user reported experiencing both difficulty in understanding the aetiology of MS and explaining to potential employers the adjustments that would be required to help facilitate a transition into employment, I experienced an intense felt sense of somehow finding a way to alleviate the service users' distress through the limited number of available interventions. Here, further questions arose; what would it mean to the service user if an immediate and direct response to his distressing experiences, thoughts and anxieties was not provided? What would it mean if the helm of the ship of returning to sustainable employment was not kept steady?

And how will the decisions made affect the working alliance? Reflecting in this way, particularly during the second year of the professional doctoral training, has meant coming to an understanding that this experience might be, as traditional psychoanalytic theory might suggest, an enactment, a counter resistance, or an issue of countertransference. Perhaps, most importantly, combining this experience and the second-year training experience had provided an opportunity to learn that at times conflict can be identified within the meaning in the presenting conflict. That is, a direct expression of the conflict may not be visible and there may be a disguised expression of unconscious processes. It is through this experience that the work of Josef Breuer and Sigmund Freud was deemed to be of significant theoretical weight and clinical significance. Equally, a desire to know more emerged.

Secondly, the neuropsychological training experience gained in Year 2 and 3 of the programme of study. This specific clinical experience facilitated a degree of wonder. That is, what did it mean to be diagnosed with RRMS? What was it like to be prescribed DMT whilst the aetiology of RRMS remained unknown? This quest for knowledge would commence with a departure from positivist methods whilst endeavouring to explore deeper processes. The quest for knowledge would also acknowledge that whilst it is not possible to have unmediated full and direct access to individual experiences, it is possible to understand those experiences and meanings through a process of co-construction. Phenomenological inquiry complemented these quests whilst corroborating with the aim of this research which was to transition away from simply reporting individual experience and toward contributing to revisions in clinical practice to foster improved packages of care. For Gergen (2015), this orients the research to future forming in that by incorporating novel approaches, reflections, and practices, a shift beyond the more traditional approach can be explored.

In summary, this chapter focused on presenting an orientation to the selected methodology and method. It was beyond the scope of the thesis to outline the varied association between phenomenology and neuropsychology. Yet, by substantiating the ontological and epistemological position, a rationale for adopting Max van Manen's hermeneutic interpretative phenomenology as the preferred method of choice was provided. Equal consideration was given to the various dimensions involved in conducting this research. What follows in the next chapter is more specifically an analysis of the experiential material derived from the research participants.

Chapter Four

Analysis

Based on the theoretical underpinnings of the previous chapter, this chapter presents the themes discerned from the experiential material derived from the research participants. These phrasings correspond to the variant and invariant themes of the reduction and are supported by excerpts taken from transcripts across each of the six participant interviews. The themes serve as navigators through the subjective accounts given on the experience of being diagnosed with RRMS and the experience of taking DMT. For purposes of clarity, each experience is organised around four existential aspects; corporeality (lived-body), relationality (lived-relation), spatiality (lived-space), and temporality (lived-time). It should be stressed that in no manner does this experiential material form fixed categories or traits. Rather, the experiential material implicates all other material, and none is more privileged than any other. Equally, there is a recognition that this analysis is only possible because the experiences have been expressed in language.

4.1 Overview of Themes

The following overview summarizes the themes discerned from the analysis process. The overview functions as a navigator to the discerned themes; whereby the theme is presented and supported by excerpts taken from the participant narratives. A phenomenological description is equally provided which communicates how participants made meaning from their lived experiences.

Experience of a Relapsing-Remitting Multiple Sclerosis diagnosis

Corporeality (Lived-Body)

- Bodily Interruption
- Fatigue
- Psychological Distress

Relationality (Lived-Relation)

- Guilt
- Power Imbalance

Spatiality (Lived-Space)

- Secrecy

Temporality (Lived-Time)

- Death

Other

- Diagnosis Inconsistencies

Experience of taking Disease-Modifying Treatment

Corporeality (Lived-Body)

- Body Object
- Decision Dilemma
- Pain
- Reformulated Life
- Complementary and Alternative Medicine

Temporality (Lived-Time)

- Future Orientated

4.2 Experiences of Relapsing-Remitting Multiple Sclerosis

4.2.1 Corporeality

4.2.1.1 Bodily Interruption

The World Health Organization (2020) considers health to be “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. If health is a question of integration, how can the experience of ill-health be conceptualised? Does ill-health permeate everyday living so that one’s human existence, one’s experience of the world and of themself becomes inferior? Or does this encounter with inferiority threaten one’s perception of being? If so, is one summoned into distillations as to their state of being? Or does one incorporate the inferiority that holds the power to threaten one’s notion of being? Experiencing ill-health seems indeed a wondrous phenomenon.

> “I worked in a call centre and I was tapping away, and my left hand just kept flicking up on its own. I found that odd. So, I massaged it … the next thing was my left leg used to freeze. So, I'd be walking somewhere, and it would just stop me dead in my track. After a couple of minutes, it would ease out. My vision would play out and it was just weird things. So, I kept going. I used to be a kind of person that something would happen in my body and I would just ignore it because at that age when you're twenty-four, you think you're invincible and it's fine. It's just random so let it happen.” (Audrey)

Much like Audrey, Naira recounts her experience:

> “I was working really long hours in retail, standing prolonged periods and I thought I'm just really tired. It progressively got so bad that I couldn't see at all. It was just, it

> was so much easier just to lay and close my eyes… I started to notice like a heaviness in my mouth and I kind of noticed that like I was brushing my teeth and I couldn't quite keep the toothpaste in my mouth. I was like “cool, I must be really tired.” And you know, “what's going on?” I was looking in the mirror and I was like “okay, that's fine” and I just kind of carried on and then like ten minutes later, I was trying to drink water and the water just spilled out my mouth and I was like “what is going on?” And then I went and looked in the mirror and half of my face had dropped.” (Naira)

In these preliminary excerpts, Audrey and Naira produce a startling account of the manner in which their physical capabilities are altered and how they are forced to adapt their relationship with their bodies. What appears especially striking is the experience of MS being marked by an interruption. That is, life is interrupted. It is this experience that results in an eventual living with perpetual interruption. Yet, Audrey and Naira respond contrarily to this interruption. As Audrey shares, “something would happen in my body and I would just ignore it because at that age when you're twenty-four, you think you're invincible and it's fine.” As the present presents itself, Audrey’s sense of body is redefined and taken for granted as it is afforded a different view when bodily interruption becomes the norm. Whereas, for Naira, the bodily interruption gives rise to several emotions: uncertainty, fear, and anxiety, whilst being an abrupt reminder of the limitations of the body. In the attention she must now pay to every act, Naira is no longer able to assume the taken-for-granted and absent-minded tranquil characteristic of drinking water. Her very ability to do so is suspended, called into question. In this incremental loss of ability, the instrumentality of her body reveals itself. The body is an entity whose readiness-to-hand can break down and such a bodily breakdown illuminates the conditions of the world. Perhaps it is this illumination that reveals how the body forms a vital part of her transcendence into the world. That is, how her body presents itself as inextricably woven into the world. From the very first breath to the moment of death. What this comes to mean is that the body is not the objective body that can be seen by others but, rather the body that is the vehicle for seeing. For one’s body has its own functions and its own ineluctable trajectory into finitude.

> “It started off as blurriness in one eye, in my right eye and the last time I had optic neuritis it was in both my eyes … Numbness I’ve had that a few times where I’ve had it like on my shoulder, my back and from my stomach and pins and needles. Memory problems… I ended up getting really bad in the beginning of my second year, so I converted to part-time in my third year. So, I ended up with my three-year degree and it turned into a five-year degree instead. I then got a job but that was full-time. It was two-hours traveling a day, plus eight-hours of work which is way too much for me.” (Sonal)

The common thread uniting the excerpts of Audrey and Naira to Sonal is that the body is the locus of intentions. For instance, projects are presented as invitations to the body’s potential undertakings, which require calculation, consideration, and configuration. Specifically, for Sonal, university no longer remains a quest for autonomy, knowledge, reason, and philosophical openness. But rather a quest for completion. In the same way employment is no longer an invitation for the surrendering of time and services in return for a salary. But rather a constant and intimate reminder related to, and a herald of, her finitude. Giving up on either would be conceding to the finality and irreversibility of her ill-health.

These introductory experiences illuminate MS related ill-health to be compounded by bodily interruptions which precede physical challenges. Such physical challenges affect an entire way of being and transform the body. It is this transformed body that is experienced through unpredictability in which a gradual decline and movement towards loss takes prominence.

What this comes to mean is that Audrey, Naira and Sonal are involuntarily required to take the viewpoint that the body is fragile and precious.

4.2.1.2 Fatigue

Fatigue is, of course, common enough in the seemingly healthy and not exclusive to MS. Yet, as in the case of the experience of the onset of MS symptoms, fatigue presents itself as a distinguishable experience:

> “That is another thing, the fatigue. The fatigue is absolutely horrendous... It’s horrendous. Sometimes I have a shower, I have to go in bed for three hours.” (Faustina)

Much like Faustina, Sonal shares a similar outlook:

> “I've got to really strategize if I'm doing something on one day. I've got to make sure, I’ve kind of figured out now how tired, I can predict how tired I'm going to get sometimes. So, I can adjust my life accordingly. Like if I’m going out shopping one day, the next day, I've got to make sure I take complete rest. So, I don't go anywhere. Maybe for the day after that and the day before maybe going shopping.” (Sonal)

Here, two noticeable features can be discerned. That is, firstly, fatigue is differentiated from the experience of tiredness and secondly, the distinguishable severity of fatigue. In seeking exploratory depth, it is interesting and important to attempt to discern what further can be known of this common experience.

> "It was to the point where I mean I actually had to purchase a voice amplifier because I was so tired and so fatigued that I couldn't speak. No one could hear me when I tried to like speak or sometimes my mouth kind of felt that it was paralyzed shut because I was just so exhausted, and I couldn't get my words out." (Sonal)

What is striking about Sonal's account is the insight she gives into the immediacy of her experience of fatigue; in that it is described as a movement toward an incapacitation of her choices, freedom, and ultimately, her voice. Carel (2016) made the argument that ill-health can take on a dualist stance. That is, as the body declines in functioning, the spirit flourishes. As "the body is tethered to its failing organs, the spirit rises free" (p.110). This is far from the case here. Sonal's experience of fatigue soon imposes on her that sense of what she is and is not permitted to do and be. Fatigue constructs a new existence, an unfamiliar landscape to be navigated. Where autonomy and familiarity once took precedence, constraint and inadequacy now command movement. This oscillation between the lived and the habitual body is characteristic of the experience of fatigue. As Sonal wishes to speak, her command requires more energy than her body can deliver and within a few moments, she experiences an incapacitation of communication, a bodily betrayal, and a loss of control. From Sonal's words, Sartre's three orders of the body can be alluded to. Sonal recognizes her experience of fatigue in the first person. She is recognized by others as a physical entity with individual characteristics: in this instance, with limitations. She then recognises herself as seen through the eyes of the other. It is this outlook of the body that is so poignantly described in her narrative. She is left alone with her incapacitation. That is, she remains in a world of agency and action, yet incapable of contributing in it as she desires, as others may desire.

Thus far, discerned from the experiential material is the common experience of a bodily interruption and in particular, fatigue. Initially, the change in bodily orientation appears disruptive and exhaustive as it stems from an overpowering loss of bodily capacity. The body adopts a conflicting will of its own, beyond the control of the self. Later, the change becomes quotidian. If this view is taken, that is, the unique body-self unity being experienced as other-than-me, it can be wondered whether this intimate encounter with physical orientation extends to psychological orientation.

4.2.1.3 Psychological Distress

Often the opening questions of a psychological assessment are ‘how do you feel?’ and ‘what do you feel?’ The questions exemplify an endeavour to commence the phenomenological reduction. The endeavour to gain entry into the subjective experience of the individual, the phenomenon, the thing itself. As outlined in the previous theme, a startling array of bodily interruptions were experienced by Audrey. What emerges now is a paralysis.

> “Sorry if I get emotional but it’s just sad (. . .) It is. You don't feel like you're worth anything anymore. Gosh. (CRYING) (. . .) You know, you feel like you are just useless (. . .) So, what's the point? Why keep trying if you haven't got the support behind you? Sorry (. . .) It's hard. I've always thought that it was a cruel disability. It's so mental. Mentally controlling. That’s where the emotions come from. The physical you get used to. So, I can't wear heels. I like wearing heels, but oh well. So, I can’t run. So, I have heavy limbs. You learn to function with what you've got. (CRYING) The mental (. . .) It's hard. It does, it just makes you feel less of a person (. . .) (CRYING)” (Audrey)

This is not a paralysis of action per se but rather a paralysis of emotion and cognition. The latter imposes on Audrey in the sense of destructive feelings of emotional suffering and instability born of ceaselessness, often inexplicable, and change that characterizes existential anguish. Destructive feelings are comprised of worthlessness, whereby Audrey is disheartened with herself and with her ability to be. Existential anguish emerges as Audrey is able to tolerate the deterioration of her body, but the deterioration of the "mental" proves damaging. Whereby the existential anguish is so deep that she is unable to prevent herself from being drained of being. It is in this dark abyss of paralysis that Audrey's ability to care for herself and to maintain her sense of being in the world that is so drastically depicted in her account.

> "You wonder eh? (. . .) I was in deep depression. It was for three years the depression. Deep depression. It takes me long, long time to accept if you can say the fact that I have this (. . .) But it's not nice to know, to know you have this and this is killing you from inside out (. . .)" (Faustina)

As a phenomenon, depression can appear to be self-evident yet simultaneously elusive. Self-evident because the depressive experience can be thought of as a universal way of being with one-self, with others, and the world. Elusive because depression was unmentioned as a distinct medical condition prior to the Third Edition of the Diagnostic and Statistical Manual of Mental Disorders of 1980. Yet, this mode of experiencing MS related ill-health is transformative of the way in which Audrey and Faustina encounter being. In the face of her experience, Audrey is summoned to undergo an existential examination of who she is. Her account reveals important elements of the individual situation and the individual life. That is, she is simultaneously confronted with the body-mind connection, deeply, seriously, and profoundly, and the customarily experience of thoughts, beliefs and emotions being altered by psychological distress. Whereas Faustina is shaped differently by her experience. Her inability to transcend the temporal barrier created by the depressive experience results in the emergence of an opaque and alien existence. This new existence marks a dramatic and intimate transformation to her life and discloses the manner in which psychological incapacity matters in RRMS. The transformation is most recognizable and damaging in the way in which Faustina is brought close to death.

Both accounts have said something compellingly important about the way in which psychological distress takes over and deplete one's will and one's strength. As situations and health status change, psychological distress presents itself in relation to being-with-others:

> "I don't really talk about it that much. I mean, my parents know that I have spoken about it in full. But there is a lot of times I don't bury it and there's some days where I'm not feeling as good as other days in regard to mental health and so I ring Samaritans because it will calm me down. I don't like to say it in front of my parents. I don't want them to worry or anything because you know they see things on TV like people you know committing suicide, which I'm not at that point or anything." (Sonal)

Sonal describes how there are occasions in which she wishes to speak about her "mental health" but grapples with the possibility of causing others' discomfort. Here, Sonal exposes a blind spot in her moral perspective. This is a crucial decision for her and whether she understands the implications of such a decision can be wondered. Yet, one thing that is clear is that she is silenced. Notwithstanding the natural consequences of this silencing on her relationship with her parents, Sonal takes comfort in deciding to contact the Samaritans. In choosing to speak to the Samaritans, she integrates her past into her present and recognizes that decisions such as these are not once in a lifetime, but rather quotidian, as circumstances, health status and relationships change. There is a limitation placed on her “mental health” and a desire to continue on in light of the understanding and acknowledgment she has from this experience.

4.2.2 Relationality

4.2.2.1 Guilt

All of the participants who contributed to the research experienced guilt. This experience of guilt was not a free-standing and physiologically based individual response, but rather an experience of guilt within a specific zone of personal relations.

> “You end up feeling guilty because like I'm twenty-odd now. Well nearly my mid twenty’s and I should be able to do these things for myself. Even when they are pushing me around in the wheelchair, I mean like they are in their fifties and I feel guilty that you know they are getting older now. They aren’t as young as they once were you know, not as fit as they once were. And they are having to push me around everywhere and they are having to do things for me. I did go to Dubai a couple years ago… but I felt guilty that my mom couldn’t enjoy herself because she was looking after me.” (Sonal)

Sonal’s experience of guilt cannot be understood separately from the relationships in which it occurs. Her experience of guilt is in relation to those moment-by-moment choices to authenticate herself. For instance, as Sonal is in an objective relationship with her parents, guilt is dialogical in the sense that responsibility to authenticate her own existence cannot be separated from her responsibility to them. Thus, Sonal cannot be guilty toward herself alone because the function of guilt is to push herself to make reparation for the difficulties caused by her situation. Experiencing guilt in this way is common given that to be a human being means to experience emotion. To not experience emotion would be a way of rejecting and escaping the matters produced by the event. Consequently, rather than placing a focus on the advantages of having access to a system of support, Sonal expresses guilt and concern toward her parents' involvement in assisting her. This appears to constitute a source of identity disruption, which can be noted in the following excerpt:

> "I've always been a bit of a yes person. I don't like letting my managers down. I don't like letting work down. Especially because I've been a civil servant for so long. It's that kind of mentality. You know, you just buckle down and get on with things and so I feel guilty. I sometimes say, I've got a disability. I can't do this. Or I can't do this the way that I used to do it. Or the way you expect me to do it. But I need to stop being so afraid of sticking up for myself." (Alexandra)

Alexandra's narrative echoes the relationality lifeworld in which she is positioned. There is an integration of the social experience of her body as an aberration, an affront to others and her body no longer being her body as she exists it. She lives with an unrecognizable body. That is, her experience of her body as dis-abled and her experience of the body as perceived by others. Eventually, her experience of guilt promotes a remedial activity, in which she minimizes guilt through conciliatory behaviours. These conciliatory behaviours shape and regulate her body whilst impeding plans and reducing actions to their impossibility.

4.2.2.2 Power Imbalance

Stories pertaining to medical practitioners who do not listen, helplessness when attempting to engage in healthcare services, and bureaucratic systems are familiar to many. Indeed, these stories presents anomalies, incongruities, and contradictions whilst arousing curiosity. Much like these dimensions, Audrey describes a rather vivid representation of what it feels like to be on the receiving end of this encounter:

> “I didn't really like this GP because it was such a quick, every time I went in there he just kept saying ‘oh it's spasms or like a trapped nerve.’ That sort of thing. So, I just put up with it and said it’s a trapped nerve and then I’d go back and say trapped nerve and he’d give me exercises to do and I was like ‘well clearly it’s not working it must be something else.’ And then, this went on for months and months.” (Audrey)

At the phenomenological centre of this primitive medical enterprise is Audrey, a patient, who has nothing but her indicators of ill-health and her need to offer; and a general practitioner, who has, or professes to have, the power to meet Audrey’s need. The offer of meeting a need, is characteristically, established on knowledge, accrued experience, and sound judgment. This suggests that the enterprise should involve a dialogical relationship, in which cumulative experiences of ill-health are understood, even in instances where the epistemic credentials of that perspective are less than impeccable. What transpires is far from conventional. As the general practitioner considers Audrey’s indicators of ill-health to be sufficient in determining the aetiology of her ill-health, the drastic lack of mutual understanding disregards her narrative to the extent that limitations are placed on the interpersonal exchange and a helplessness prevails. Equally, it should be carefully noticed that Audrey is willing to recognize herself as a patient. That is, her intention is not an implementation of defeatism. More accurately, it is an evaluation of what has been lost, what is no longer viable, and wanting to transcend the shadows of ill-health into the light of wellness.

> “We went to the hospital and they said it was a bell’s palsy. They gave me some steroids and I was like ‘this is just not okay.’ And I kind of went back to the general practitioner and I was like ‘look, I don't know what's going on with me, you know, I've also started to experience numbness in my hand.’ So, they put me through an MRI scan, and you know, I went and had an eye test just to rule out anything optical. They thought there might be a brain tumour. There wasn't a brain tumour. Well, okay that must mean I'm fine … I thought ‘well, it's kind of been like four weeks and I haven't heard anything.’ Called the GP back and she said ‘oh, you know you might want to be prepared that it's probably MS.’ And I was like ‘well, have you got the MRI scan back?’ And she was like ‘no.’ And I was like ‘so on what basis are you saying that?’ And she couldn’t really answer my question.” (Naira).

Naira equally and explicitly identifies the power imbalance between herself and the general practitioner. This power imbalance reformulates her body into a disenchanted, inanimate mechanism, suitable for scientific investigation. It is this disparity in collective interpretative resources that places her at a disadvantage when attempting to make sense of her indicators of ill-health. It is this experience that shows in a dispassionate manner the conditions as they actually exist in the medical enterprise. Amidst this imbalance of power, Faustina voiced a great deal of opinion in relation to the style of interaction:

> “The doctors, they say ‘go to your country and ask what that is because we cannot do anything about it.’ That was in a hospital in London. In the ***** hospital in London. I said, ‘well, my country - I live here.’ You know, so I cannot say nothing… The GP sent me to ***** to see Dr. ***** but they say, ‘if it's urgent then we send you for an MRI scan in three months – if it’s urgent.’ I said, I said; ‘don't worry, I will go to

> my country. I will do all the exams in there because I cannot wait three months without seeing, you know, without knowing what is going on because no one say nothing to me.' So, I went to my country. They make the scan and that was in February 2004. Made the scan and in there they give me the news. So, I come in the UK. I am living in the UK – why am I living in the UK?" (Faustina)

Faustina's narrative adds another layer to the experience of an imbalance in power. Besides the policies and practices of healthcare services being unjust, Faustina's narrative is downgraded as a result of being unable to communicate in a direct manner her indicators of ill-health. Ultimately, she is only able to communicate her ill-health with those with whom she shares a sense of solidarity and unity. This is not to say that the primitive medical enterprise is inevitably and unavoidably unjust, but rather particular experiences generate injustice. Experiences on the other end of the spectrum are known:

> "So, I ended up in hospital and everything happened so quickly like in that week. I had like an MRI because of a lumbar puncture and all those things and although they couldn't give me like officially hundred per cent, they had to wait for lumbar puncture results. They said 'yeah, we're pretty sure that you've got MS.' And then I think a couple months later, I had the formal diagnosis." (Savannah)

Savannah's extract marks an overt and implicit reference to the bodily transformation which remains unknown until she comes face-to-face with it. That is, until she comes face-to-face with herself transformed. In granting a certain cogency, acceptance does not come through awareness of an incremental loss of ability; but paradoxically through the experience of being diagnosed.

> “I said, ‘but what is this multiple sclerosis? I don't understand it.’ And I still remember the look she gave me, and I was like ‘what?’ She said, ‘I'm a multiple-sclerosis consultant. I specialize in multiple sclerosis. I work with people that have multiple-sclerosis.’ I said, ‘so, you're telling me I got it?’ She said, ‘Yeah.’ I said, ‘so, when did you find out?’ She went, she looked at me and said, ‘when they released you from hospital did no one tell you?’ I said, ‘no’ and I told her they said, ‘they are going to refer me to you and we're going to work together to find out what it was.’ And she said, ‘they should have told you.’ She went, ‘they referred you to me because you have relapsing-remitting multiple-sclerosis.’ I couldn’t believe it. I couldn’t accept it. I really couldn’t.” (Audrey)

Here, to be diagnosed means to be identified. The medical practitioner who diagnosed Audrey thereby identified her existence, her very being. This is not the same as being identified by a friend, family member or colleague. When identified by a friend, the cognitive experience is revived so that this friend becomes part of the experience, the life history. The friend exists and is now memorable. However, the experience of being identified by a medical practitioner is inextricably intertwined with selfhood, identity, and the patient’s sense of personal being. With this latter identification, the experience of receiving a diagnosis begins to emerge. That is, diagnosis marks the beginning of a particular association between the individual and the self, the individual and the medical practitioner, and the individual and the other. As Audrey’s narrative indicates, the diagnosis moment is captured by the transformation of symptoms into a less subjective entity. The symptoms are structured into explicatory relationships, explanations, and predictions of ill-health. In a related vein, of importance is how the disparity in communicating the diagnosis not only causes disbelief but a period of intense felt denial.

> “So, I was diagnosed in my first year of university … I was just having fun with my friends I decided to go and open up my post. And then, I saw the letter and I read it and it said, ‘I can now confirm that your symptoms and stuff is due to MS after having a scan.’ And it was pretty hard. You know to digest that. I didn't really know that much about MS at the time. I was pretty young. I haven't really heard of it that much and so I googled it which isn't a good thing to do. When you google things you know it tells you the worst scenario, and I remember telling my parents about it and they were obviously in shock as well, and I think they hid a lot of how they thought from me to try and protect me because my dad I remember kept saying ‘no don't worry about it, you'll be fine, you're okay’ and all that sort of stuff but that didn't really help me because I felt like I was kind of alone in processing it.” (Sonal)

Standing at this turning point of a diagnosis is a relationality which manifests itself in both familiarity and unfamiliarity. Familiarity in that the world lies spread out before Sonal as a sphere for action and her body is pure instrumentality taking the world for its domain. And unfamiliarity in which Sonal experiences herself under the medical gaze. The self is experienced as having limits just as an ordinary object has limits. It has become impaired through ill-health. That is, it is intruded upon, and intrudes into awareness. At the same time, whereas the medical practitioner sees symptoms, Sonal experiences these symptoms as answers to the demands of her present life situation. Another turning point is the internal experience of aloneness manifested by the adoption of technology. The emphasis on convenience and impersonal technological mechanisms serves to separate Sonal from medical practitioners’ and succeeds in fostering feelings of disconnection and loneliness. There is evidence to suggest that Sonal’s interaction with her parents becomes increasingly dissatisfying since technology produces an impersonal manner of relating. That is, a mode of relating to one another in a mechanical way rather than as beings in relationships.

4.2.3 Spatiality

4.2.3.1 Secrecy

Another dimension in the experience of being diagnosed is the encounter with scientific and medical terminology. Participants described how symptoms were no longer a private and subjective experience of bodily interruption. Rather, symptoms reflected a transition toward a medical ontology in which universal understanding and meanings was associated.

> “When I was first diagnosed my parents and my younger sister were with me and I told them. I'm one of seven children. So, I told them I don't want anybody else to know until I deal with this myself. I don't want to tell anyone. So, for a few months I didn't confide in the rest of my family. I just kept it within the four of us that were in the room at the time that I was diagnosed. I think because I was in a kind of a mindset of denial really you know, and I wasn't sure what I would tell people anyway because I didn't fully understand what I was going through myself. So, for the first few months after I was diagnosed nothing changed. I kept on with my responsibilities and I kind of buried my mind in the sand as it was. Like I just carried on as if nothing had happened or at least other people around me couldn't notice that anything was really going on with me.” (Alexandra)

By the end of this passage, Alexandra's experience of a diagnosis is not the overriding matter. The theme, rather, is her experience of secrecy. Her narrative places focus on the way she is granted control over those she wished not to inform of her diagnosis and how she allowed herself to maintain normality. To further explore this theme, it is relevant to mentioned that secrecy is dissimilar to lying in that the latter involves deception, whereby the former may not necessarily incorporate deception. Equally, secrecy is dissimilar to the practice of privacy. Privacy is in essence a non-relational experience, whilst secrecy at all times implicates the other from whom a secret is kept, or with whom a secret is shared with. With this in mind, it is possible to discern the experience of secrecy for Alexandra. The connectedness between Alexandra and the other can take the form of self-conscious emotions. As Alexandra experiences these self-conscious emotions, she is prevented from thinking about how her diagnosis is related to self-representation. Rather, she becomes motivated by her desire to protect others from her diagnosis in order to arrive at a satisfying self-identity. For instance, "I just carried on as if nothing had happened or at least other people around me couldn't notice that anything was really going on with me." It is here that her passage provides an orientation into how secrecy alters relational possibilities.

Within this context, it is necessary to explicate spatiality into the way in which this experience of secrecy is characterized. As the interview progressed, Alexandra shared "I was maybe either in my bedroom or wherever when I was on my own and then at that point, I was doing research and probably looking at things I shouldn't really have been looking at. You know, unhealthy images of MS. I was predominately looking at worst case scenarios and then upsetting myself even more. And then dealing with those emotions on my own and suppressing them." It is here that secrecy incorporates not only an alteration to relational possibilities, but a change in surrounding spatiality. Just as an alteration of relational possibilities is experienced as a self-conscious emotional change, lived spatiality is characterized by both curtailment of spatial possibilities and an abrupt descent of limits onto a world previously larger, freer, more open. Spatiality relates to Alexandra's immersion into the world of her "bedroom", which she now navigates with challenge. Her "bedroom" intended by her body as a repository for rest, now takes another dimension. By maintaining the secrecy of a diagnosis, her "bedroom", a familiar place she inhabits, changes her way of being. In the face of her experience, secrecy creates spaces in which vigilance replaces ease and uncertainty creates tension and dis-ease. What is striking is how Alexandra's experience of solitude comes not only from maintaining the secrecy of her diagnosis and the isolation of her bedroom but an unwillingness to recognize herself within the stillness of her emotions.

4.2.4 Temporality

4.2.4.1 Death

> "At the time I was like twenty-two and I was like, 'you're telling me that my prognosis is bad?' He said things like, 'if I was your sister, this is what I would tell you to do.' And I was just like, 'what do you mean if I was your sister?' 'What is this crap?' Like it was so unprofessional. And I remember leaving and just sitting in the car and I was like 'I'm going to die.' (.) 'I'm going to die.' (.) I called my now husband and I just said, 'this is the situation, if you want to go, you can go.' (CRYING) And I don't think he really understood at the time, but he was like 'don't be stupid, we will deal with it as it comes.' And it was just like really bad time for a really long time. Like for six months, I wouldn't really leave the house. I was really scared." (Naira)

Underlying this passage is the movement of Naira’s suffering and solitude toward death. Here, diagnosis represents a threat to life. Diagnosis represents death as a structural component, a fulcrum point in which, diagnosis is the end of life. Diagnosis is the end of her time. The moment of diagnosis is the extinction of the self and the final experience of self-awareness. This moment set limits to her existence and to confound this inevitable vicissitude of time, she appears to no longer be able to be able and expresses this further in her intimate relationship. In doing so, she realises that death is subjectively inconceivable in that death does not happen to those who die, but to those who grieve. Just as no one individual cannot live another individual’s life, “no one can take the Other’s dying away from him” (Heidegger, 1962, p. 284). Heidegger (1962) proposed human being-in-the-world is permanently a being-toward-death. In other words, just as the experience of life serves as a backdrop to the meaning of death, the experience of death serves as a backdrop to the meaning of life. Death, of course, can be expressed as a philosophical matter, but it remains obvious that the concept is not purely theoretical but a highly subjective matter that touches each human life. Thus, in the lived experience of a diagnosis serving as a backdrop to death, some experience death as an urge toward being engulfed:

> “It's difficult. When you're physically fit being told that you've got this condition, and this is the potential outcome … I'm a control freak just generally. I plan my life. I sort of say ‘okay, I want to be married by the time I am this age. I want to have children by this age. I want to have this amount of children.’ And a lot of my plans now, in my mind, are unachievable or I’ve kind of changed. I've had to change my outlook on life and live more in the moment and I think stop taking time for granted. So that's, I think emotionally, it's been tough. It's been much more harder than that. I mean, I had really serious lows and I think the way that I kind of dealt with it was akin to the

> grieving process so there was that lots of stages that I went through where I finally got to a stage of acceptance, but it took me a while to get there." (Alexandra)

At first reading, a shift in Alexandra's intentionality can be discerned in that her sense of self is revised and redefined in the face of an ever-increasing bodily interruption. Not only does this lead to an interruption of her temporality but a dynamic process of grief emerges. But what is it that can be known about diagnosis, death, and grief from a phenomenological perspective? Death is present in health, as life and death are intimately linked. Death is also present on the experiential spectrum of ill-health and inevitably constructs part of the ill-health experience. Yet, by revealing the finitude of existential life, death and diagnosis represent an edifying effect. That is, the common thread uniting the narratives of Naira and Alexandra is the way their experiences impart courage, resoluteness, whilst nourishing their capacity for compassion. The narratives lay bare who each individual is beneath the attempt to displace the death anxiety which diagnosis has fast-tracked. Once death is conceptualised, life's purposes and priorities reorganise themselves. This visceral awareness reveals a fresh new way of life, infinitely valuable, uncertain, and mysterious.

4.2.5 Other

4.2.5.1 Diagnosis Inconsistencies

In general medicine, diagnosis provides an economical means of communicating precisely the presence of actual bodily disease or the presence of organic disorder. To make a diagnosis, the medical practitioner observes the body through a physical examination. This may reveal unusual signs, which may or may not be accompanied by subjective observations made by the patient. Both are often checked against laboratory test results and/or radiological reports. Diagnosis then becomes identification. That is, the medical practitioner attempts to identify the patient through diagnosis. Not only then is a patient manufactured through diagnosis, but a disease and/or disorder is made real and noticeable. By receiving a diagnosis, the language of science permeates everyday living so that an individual’s existence, experience of the world, and of themselves becomes scientized.

> “The hospital wrote to me to say that they've made a mistake and actually there were lesions on my brain and that I should return for a diagnosis of MS. So, I did return, and I asked for a second MRI because I wasn't confident in the original findings and because of the issues. And I was given a second MRI in August 2018, which did confirm new lesions within time and space.” (Alexandra)

Naira provides a similar indication of the diagnosis process:

> “I went and saw a GP and they said it might be labyrinthitis. And I was like ‘oh crikey, ok, well that's come back in a really short amount of time’ and I didn't think anything of it.” (Naira)

At an earlier stage in the interview, Alexandra described receiving an incorrect diagnosis. It could be speculated that receiving an incorrect diagnosis would mean to have no acknowledgement of her very being. Yet, the extract above shows that even with a correct diagnosis she experiences difficulty in redefining the new bounds for her capability and that she comes to understand diagnosis with a disbelief. Similarly, for Naira, diagnosis was a renunciation of the severity of her ill-health. During the interviews, other participants descriptions of receiving a diagnosis included: adopting a mode of unavailability; a reformulation of self-concept; the future being a source of doubt and restriction; despair increasing through observation of other PwMS; and neurological examinations strengthening feelings of uncertainty. These dimensions indicate toward the diagnosis of RRMS being a non-linear and continually shifting process. That is, as experiences of the body change over time, these experiences arise from the living flow of everyday existence.

> "Everything I kind of knew was taken away. Like wearing heels was … No one talks you through that journey. No one explains that there are certain things that you do naturally that you're not going to be able to and I think that's the acceptance of it because I loved wearing high heels. I loved partying. Couldn't party anymore. I loved being sociable and now I'm just content in my own company… It changed my life completely and, in a sense, it just took over… I just cried. I felt lonely and I was angry with the world. Angry with everything. And I was depressed… I just wasn't me. I was fighting with everything I knew… I wasn't myself. I was a stranger in my own body." (Audrey)

Here, diagnosis marks a deepening erosion of Audrey's freedom to live. A previously open future is now diminished due to the progressiveness and unpredictability of RRMS. Lifestyle undertakings lose their habitual element and turn out to be either taxing or extinct. Such undertakings are no longer immediate possibilities. What was previously done unthinkingly, without preparation and minimal effort, is now an upsetting and explicit reminder of the past and of a great change. Thus, not only does Audrey's diagnosis encapsulate a restricted freedom to live but her desire to do so. In other words, by lacking the desire to act, then an actual incapacity to act becomes, paradoxically, secondary.

As outlined, the experience of a diagnosis of RRMS is a profound realization of bodily vulnerability and finitude. Equally, it can be accurate to discern that receiving a diagnosis can lead to unintended and unexpected gains such as insight, maturity, and clarity. Such gains are brought to the fore in the following excerpts:

> “You just never really know if you're going to be well enough. Also, it has, that’s one of the main reasons why I changed job roles. But that was the positive. Like it was something I wanted to do that was better for me but it did kind of stem from the fact that can I deliver the role I was doing to the best I could because I just was so up and down with being unwell. So, I really, I think it’s just been, trial and error with learning to just get on with things and not worrying about what it will be like. I just had to start being like ‘if I want do it, I'm going to plan to do it’ because you never know. I might be fine or I might not.” (Savannah)

Naira, shares a similar sentiment:

> “You can't feel your hand today but you can feel the wind on your face. The sun is shining, someone smiled at you. Today, you're walking. Today, you can see the colour of the leaves… it's hard to just be like its God and God's will and that's okay… I found new purpose. I just started to connect with others differently and you know like it made me have a new appreciation for life.” (Naira)

Here, diagnosis awakens both Savannah and Naira from the slumber of shallow preoccupations to the preciousness and fragility of life. Both begin to see things more clearly and vividly. Life is then not some mysterious vital force, but precisely an ongoing restabilizing process. Specifically, Naira’s reference to “God and God's will” reflects an Islamic discourse and a future orientation. This future orientation is best understood through ‘entwurf' (translated to projection) (Heidegger, 1962, p.185). Here, Naira's projection defines her character and identity. This, claims Heidegger, is the essence of human existence: the capability to be this or an alternative kind of individual, to become something, even if this does not ensue from a conscious decision to be this kind of individual engaged in this activity.

4.3 Experiences of Disease-Modifying Treatment

4.3.1 Corporeality

4.3.1.1 Body Object

Subjecting the experience of receiving a diagnosis to an analysis resulted in discerning the dynamic movement of the lived body into the objective body. Not only did the experience throw the lived body back on itself, even more distinctively, it called the lived body into question. With the body now brought into focus, an endeavour is undertaken as to what this mode of experiencing might mean.

> "My body ached all the time. All I wanted to do was sleep all the time. I wasn't myself. I was a stranger in my own body" and "you're in a body that is not yours because you don't have control." (Audrey)

It is this experience that exacerbates a similar type of alienation of the lived body with which menaces Sonal:

> "When I get a flare up or a relapse then I start to do the whole feeling sorry for myself and things like that. Then I find it harder to then, this summer I kind of flared up pretty badly. And so, it kind of just brought back, I don't know the feelings are like

> ‘oh, you know, I’ve got this MS thing. It’s going to happen for life. I’m this bad already, how’s it going to be like in the future.’” (Sonal)

In this passage, the language of nosology permeates Sonal’s experience to the extent that her encounter with medical terminology becomes enmeshed into her ontological constitution of being. That said, within the confines of nosology, medical language reigns supreme and Sonal’s subjectivity seems the least determinative element of her health. In the midst of the experience, her identity as a structure which is unable to persist beyond the flow of circumstances and temporality is discerned through her words. That is, previous endeavours are reminders of the horizons of engagement and the capability of what her body could do without thought which are now out of bounds. This new disorientation absorbs her, destabilises avenues of involvement and becomes a viable source of definition of her-self. In some way, she feels extraneous from her lived body and appears to complement, continue, and regain a sense of bodily self through questioning.

The common thread uniting the account of Sonal to that of Audrey is the experience of the lived body transitioning. Audrey introduces a palpable pain engulfed deep within the lived body. That is, Audrey is unable to separate herself from the pain, which is continuous over time and judges herself largely, or even exclusively, in terms of her ability to have autonomy over her body. At the same time, the unexpected feeling of a powerlessness captures the fragile dimension of the body. It is this powerlessness that is narrated as an unrelenting compromise of her lived body. Both accounts are indicative of the manner in which the lived body and emotions are inseparable. That is, how both elements permeate their existence, and how their lived body and their emotional well-being are the same matter. For both Audrey and Sonal, as is the case with the other participants, the lived body becomes a mechanism to repair. A mechanism of forging and renewing relationship with the world through an altered sense of embodiment.

4.3.1.2 Decision Dilemma

There is, as yet no curative treatment for MS. There is, however, DMT which can reduce disease progression in the relapsing phenotypes of MS (Amato et al., 2020). Studies such as this are adequately understood and vastly documented within the literature. Yet, it is not until the question of how a DMT agent is decided upon is raised that further analysis is warranted. In the following excerpt, Faustina provides an indication of the experience of selecting a DMT agent:

> "The damage can be enormous and cannot be repaired so you have to put in the balance what would you prefer; gambling that something will happen to you or put injections and you know you are a little bit preventing the course. It's a very personal thing." (Faustina)

Faustina's account alludes to a deeper feature of the experience of deciding upon a DMT agent in that she feels torn between making a rational choice regarding her ill-health and losing the freedom to manage an inevitable decline of her body. Other participants shared a similar personal experience of their decision-making process:

> "He (the neurologist) was talking about injections, which I didn't want to do and so he said, 'luckily there is a clinical trial where there is tablet form.' And so, I felt a lot happier knowing that I could take a tablet form as opposed to an injection form. I always knew that I wanted to take something for it. I wasn't just going to let it slide and just leave it." (Sonal)

In the next passage, Savannah explains how she came to decide upon a DMT agent:

> “I'd never went for the infusion because it’s such a big decision to make on your own and you’re always like ‘is this the right thing…’ It was such a big step and I just, I guess in my head, I was being like you know ‘I don't need that. I don't need that. Like I'll be OK with just a tablet.’ Like I didn't want to take such a bold step when I thought that I could handle it or manage it with the tablet.” (Savannah)

Amidst the decision-making process, both Sonal and Savannah express reservation with specific methods of administrating DMT. Before engaging in an analysis, it is important to acknowledge how modes of administering DMT have been developed from subcutaneous injections to intravenous infusions and now to oral tablets (Ransohoff, 2015). The results of which are profound. Whereas Sonal relies on the guidance of a medical practitioner, Savannah appraises DMT through the way she understands who she is and what she wants to be. To see what this might mean, it is necessary to explicate some of the dimensions characterising each choice. Medical practitioners have a duty to keep professional knowledge and skills up to date (General Medical Council, 2020). In doing so, they use this knowledge for the purposes of building trust and for the purposes of healing. In the experience of Sonal, this primitive medical enterprise allows her operational causes of concerns to be relieved. Equally, avoiding injections valorises her individuality in that a reawakening takes place. That is, Sonal wishes to not only overcome her ill-health but seeks to return her body to its normative docility.

By contrast, Savannah’s experience highlights relational and emotional concerns. Initially, deliberating over the prospect of taking infusions gives rise to a confrontation with the isolating experience of a neurological disease. This disease opens Savannah up to her emotional life in a way that may be purely physiological in the first instance. Yet, it is this deliberation of DMT agent that is indicative of a new world journey of coping. It is at this moment that discovery begins. Firstly, the oral tablet mode of administration is selected as it is perceived as potentially preserving a degree of normalcy. The upshot of this is a feeling of immediate registration of how the body has changed. Secondly, by eliminating the prospect of taking infusions, Savannah eliminates the prospect of curtailing her ability to manage freely the medications. Thus, DMT does not exclusively mean treatment in the sense of a reduction of disease but rather treatment in the sense of an overall self-vitality embodied as a rich matrix of meaning within the world.

4.3.1.3 Pain

> "I love it, but I hate it. If you can understand? (Faustina).
>
> "Can you tell me a bit about it?" (Dipesh).
>
> "I love it because I think help me really help me you know, and I hate it because I hate the needles." (Faustina)

Faustina's explicit account highlights a valuable dimension in discerning the experience of taking DMT. In specific reference to subcutaneous injection, her experience does not appear to resemble a choice. Rather, she is forced into a predicament with what appears to be only one feasible conjecture. On the one hand, injections are perceived as an obligation to the extent that Faustina is forced to take a DMT agent in order to be helped. The burden of which may not only reflect the degree of side effects and risk associated with taking an injection agent but may be associated to the obstacles PwRRMS are required to overcome. On the other hand, it is this dynamic and fragile dimension of DMT administration that has a revitalizing potential. That is, as injections serve as an intimate reminder of her corporeal discomfort, Faustina's experiential horizon change. This process becomes important in that when confronted with the discomforting DMT experience, Faustina’s response is underpinned and fuelled by a felt and deep sense of resilience.

> “The first day’s really hard core because my eye that I was already having trouble with just completely went black … I kept noticing, like my body was going from one extreme to the other. Like one minute, I was freezing cold and had so many blankets on me. I just couldn't stop shaking and then the next minute I was boiling hot and needed fans on me and stuff like that. So, the first day was really bad and then in the night I was quite sick and then after that kind of each day got a little better. I think the Tuesday and Wednesday weren't nice but because they weren't as bad as the first day, I handled them a bit better and then I remembered the Thursday being fine because I have had the steroids to start with and I think they were pretty nasty as well like they can do a lot of damage. The Thursday, I felt really, really good and then the Friday was a bit rubbish again.” (Savannah)

In contrast to Faustina, Savannah’s account speaks to the idea that the DMT experience intensifies the awareness of the body. Specifically, Savannah’s account brings to the fore the everyday absence of awareness of how the body over time acquires a unique and habitual way of relating to its world. Now that the body’s capacity experiences alteration and compromise, what prevails is a pained body. This continues to be focal in Savannah’s experience as it brings into question the healing potential of DMT which is a separate issue from the body as an isolated mechanism requiring repair.

Perhaps the hallmark of Savannah’s experience is the way in which it resembles Faustina’s. That is, the way the familiarity of the body is taken away as they become more out of step with their regime of corporeal control. Whilst there is an alienation, there is a connectedness to this new physical condition. It is this constant interplay that represents their new world view. Not only is there a motivation and desire to continue with future treatment but treatment represents a relational dimension. That is, new and original relationships with various elements of their life world through their reformed sense of embodiment. With this in mind, it is yet to be seen if this results in overcoming the impalpability of expressing the pain which resides somewhere deep inside of the body which others have described:

> "It felt as if I've been hit by a bus that your whole body is aching. You feel bone pain … It's almost as if I could feel my bone marrow getting into work you know. Even my spine. Like the insides of my bones hurt." (Alexandra)

4.3.1.4 Reformulated Life

The experiences below describe how DMT alters the influence of RRMS to the extent that life no longer represents the boundaries of ill-health, but rather a restabilizing process. That is, where once Alexandra and Naira were dragged out of the tranquil pace of day-to-day life and plunged into a life which failed to make any sense in the manner it previously did, DMT reformulates life.

> "I felt like I was reborn. I was a completely new person. And this is what life should feel like. You know, I don't really struggle. I wasn't struggling with fatigue as much as I was prior to having treatment. It was like I had a new lease of life." (Alexandra)

Much like Alexandra, Naira shares a similar experience:

> “I found new purpose. I just started to connect with others differently and you know like it made me have a new appreciation for life.” (Naira)

It would seem appropriate to inquire further as to how these textual portrayals, namely, ‘reborn’, ‘a completely new person’, ‘a new lease of life’, and ‘a new appreciation for life’ can discern the experience of taking DMT. The experience of taking DMT awakens Alexandra and Naira from the slumber of preoccupations surrounding the uncertainty of RRMS into the preciousness of life. Up until that time, as RRMS closed in, it did so by depleting their contingency and emotional resource. Through taking DMT, both cross into a new horizon accompanied by cohesion and purpose. The plans of the past which once appeared saturated with difficulty are reconstructed. The endeavours which once provided nourishment and enrichment are re-engaged with. A new real value is revealed. That is, the life of an unknown nature and passively endured is replaced with a boundless flow of life’s everyday spontaneity. Where in ill-health the body dominated action (i.e., Alexandra re-planning her life due to being diagnosed with RRMS (*see* 4.4.1 Death)), now the project dominates action (i.e., navigating the world with her ‘new lease of life’). The new recognition that emerges allows both Alexandra and Naira to refuse to be limited by the incapacitation of their bodies. Thereby enacting their freedom as a deliberative focal point despite of their ill-health.

A point of further ponderance extends to whether DMT can mitigate the existential suffering associated with RRMS and put an end to the perceived finitude:

> “The fact that I've had Lemtrada has definitely given me a sense of security because I feel as if I have some armour on you know to protect me from relapses … I felt like I had a new lease of life where I felt invincible in a way. These are things other people

> take for granted. Being able to walk for two hours a day and still go to the gym. And do a full day's work and then not feeling like you're dead at the end of the day because when I'm coming home at the end of the day, I'm still making myself dinner. Or watching something on TV and not falling asleep in the middle of whatever I am watching. I was socializing more. So, I noticed that before having treatment, I'll make excuses not to go out on the weekends with my friends because I was just too tired to go. I couldn't be bothered, I'd say. But really and truly it is because I was too tired. The thought of going out is what I couldn't be bothered about. But yeah, I was making more effort to socialize. I had the energy to socialize. I had the mental capacity and the mental energy to actually socialize with people. So, I think for me Lemtrada has been a godsend." (Alexandra)

By submitting this passage to an analysis, a feature that appears particularly intriguing is the experience of taking DMT serving as a vehicle for a new relationship with the body to be formed. Alexandra's ill-health which was a condition of the past becomes the sole content of the moment. That is, whilst she had ceased to live with the realities of her diagnosis, DMT engages her into a new relationship with her body. The process begins with a recognition of her body's existence. The essential efficiency of her body only seizes her attention when she could no longer just act from the body, but when she is required to act toward it. This process of objectification enables Alexandra to revalue the dimensions of her body. It is here that the experience of taking DMT is marked by an explicit awareness and absorption of the presence of the body. In her case, the body reveals itself originally as a new order. As a result, life regains its enchantment. It is turned into a sudden incentive to live. As the world grows dearer to Alexandra, steps are taken on the road toward attuning with her body. That is, the body that interacts with the environment, the body that is drawn together, and the body that encloses her.

In this new way, somewhat paradoxically, the progressive inevitably of RRMS makes life very much alive. And just as DMT allows for a variation of life, life comes to be understood in terms of the body.

4.3.1.5 Complementary and Alternative Medicine

As outlined in the previous theme, a dimension of the experience of taking DMT is that the body engages in a restabilizing process. It is in this process that the more insistently the body's capacity is rekindled, the more revitalizing the potential for participation in life. Yet, it is in reference to the dynamic healing process that Naira shares an experience of healing through an alternative agent of treatment:

> "He (*in reference to a work colleague*) actually gave me a book on mindfulness (.) (TEARS). Changed my life (.) Like genuinely (. . .) Sorry (. . .) I worked through it and I think it helped me to learn to appreciate the small things in life again. Just small like ok so either you can't feel your hand today, but you can feel the wind on your face. The sun is shining, someone smiled at you. Today, you're walking. Today, you can see the colour of the leaves and it was really, it was so, you know, it literally saved my life. He saved my life with that book." (Naira)

Naira's desire to use CAM stems from accepting a gift in which the preciousness of giving and receiving is of considerable intrigue. The act of giving a gift can extend to a plethora of possibilities including gifting for the purposes of gratitude or for inner satisfaction. Either way, it is in this manner that this ordinary intention creates an exchange. A focal experience, 'he saved my life with that book.' It is indeed that this unfolding experience is grounded by two different sets of insights: (i) the refashioning of a new emotionally meaningful life through a reformed sense of embodiment; and (ii) alternative treatment recognizing the connection between the mind and body.

Naira describes her reformed experience of embodiment eloquently. The meaning of life as she lives it and the nature of personal actions as she experiences them are refashioned through a process of self-transformation and self-observation. This process creates a new life view focused on the interconnection between the mind and the body, which is directly disciplined by the attention given to the physical sensations that form the life of the body and the continuous interconnection with the life of the mind. It is this new experience that permeates the affairs of her everyday life. Previously (*see* 4.4.1 Death) Naira's experience of RRMS was characterized by a trajectory toward death. Now, her experience appears to transcend hedonic and eudaimonic well-being. That is, she experiences a sense of stability and composure. A state of equanimity. This organic occurrence evokes an understanding that is otherwise beyond reach. Through this untrivialized dimension, the phenomenology of this total sensation can be further discerned. Naira's increased compassion for her body subsequently extends to embracing the nourishing gaze of the sun, the warmth of a smile, the liberty associated with walking, and the beauty that is the changing of the seasons. Through direct experience, her realization is then that life and relationships can be experienced as pleasurable, meaningful, and full of intrinsic existence.

Audrey shares her experience of taking an alternative agent of treatment:

> "The deactivator has changed my life and it sounds so big making that statement but it's true. Before it, I was very content to sit in the house be depressive and not do anything and try to do something every so often like work wise. But that allowed the

> negative thoughts to take over and say, “I'm not good enough”. The activator now has allowed me to be more active for starters. It's allowed me to sleep. It's allowed a lot of symptoms to be forgotten about because they're not happening anymore. My eyes stopped spinning. My speech stopped slurring as often. My legs stop being as heavy as they were, the weirdest thing is that I used to have numb feet, I don't have numb feet no more. I knocked my little toe, the other day and felt it (LAUGHTER). It's giving me a chance to go to the gym, to be more active. It’s allowed me to look up straighter. It's allowed me to have positive visions amongst the dark visions.” (Audrey)

Audrey’s excerpt points to fundamental life feelings that are very much tied up in the bodily experience. What is striking about this embodied interweaving of life and body is that Audrey initially experienced this engagement as melancholic, inconsequential, and without purpose. Further, Audrey’s reference to her ‘symptoms’ is indicative of an epistemological conceptualisation of the body grounded on anatomical, physiological, and biochemical characteristics. Yet, by selecting an herbal ‘deactivator’ (taken in capsule form and consisting of milk thistle, green tea, ashwagandha, bacopa, and turmeric) as an agent of treatment, a departure from this restorative medicine is represented. Of this sort yields a specific alteration. Audrey’s body is validated, respected, and enlightened. It is now that her body can be managed at various levels and degrees within, or tangential to, life’s encounters. Of note is the specific ways in which Audrey is enabled to both establish new relationships to the world and to rekindle old relationships in new ways. The nature of how Audrey grows, how she frees herself from ill-health suggests that the alternative agent has a more pressing relevance in that she rediscovers and restores her body's connection to life. Not only does this agent facilitate the emotional side of re-embodiment but fosters a recognition between the mind and body.

Whereas the experience of DMT is characterized by the lived body becoming a mechanism to repaired, that is, a mechanism for reforming relationship with the world through an altered sense of embodiment; CAM medicine alters; corporeal identity, that is, the taken-for-granted awareness of the world, and the relations with life.

4.3.2 Temporality

4.3.2.1 Future Orientated

Similar to the exploration of receiving a diagnosis (*see* 4.4 Temporality), consideration is given to the experience of taking DMT in the context of both temporal and experiential time.

> “The idea of having to inject myself once a week or twice a week and having flu like symptoms because of the injections for the next twenty or thirty years of my life and it not really meaning anything in the end was a waste of my time and energy. You know, that was how I feel about it. So, I looked at Lemtrada because it's something that will cause definitely causes a permanent change and that the clinical trials are quite promising at least for about fifty per cent of people. And it's something that you, ideally you can do twice and then that’s you forever, hopefully.” (Alexandra)

Savannah shares the following outlook:

> “The second-round next year that potentially could be for life. So, if unless like some people have to have a top up but that to me is a massive pro because as opposed to the tablets where I would be having to take them for the rest of my life, they don't really know the long-term effect of them. It’s quite nice to know that there might be

> an end in sight, not to be like cured or anything, but at least to be off medication.”
> (Savannah)

These passages specify time not being viewed as a succession of seconds, minutes, and hours, but rather as a network of intentionality. As Alexandra and Savannah live in an aura of ill-health, their excerpts present a perception of wanting to overcome the incoherence of the present. For instance, enduring the physical demands of impaired embodiment grounds Alexandra in the present moment before the future is thought of. That is, free of DMT.

Perhaps the most poignant description of an awareness of time occurred in the context of ‘waste of my time’. This experience is a cyclical time which unfolds in a chronology of injection administration with intervals of further mounted illness. Time does not mean days and months and years. Rather, time resembles a symphony, a crescendo of symptoms, unforgiving interludes of relapses, and the existence of a trudging determination. Thus, Alexandra’s experience is based on both the distant and immediate future. Although the latter represented uncertainty and unpredictability, there is a realization of at least some choice in it. That is, whilst the inevitable limited nature of her existence is acknowledged, she presents a perspective of how her time can be given new meaning. It is here that the treatment selection process is permeated a temporal dimension.

By contrast, Savannah’s time is characterized by the present being transposed into an imagined future. She is at a standstill, or at least by deliberating DMT, her time is re-divided, re-ordered, and re-arranged. She is compelled to make choices that serve to affect her perception of the passage of time. This perception is debilitating in the sense that time itself becomes a precious commodity, and the more she attempts to hold on to it, the faster she experiences it as going.

Given the nature of her diagnosis, the future assumes an inherently problematic quality. In thinking of projects, she can never be sure what her physical status will be at some future point in time meaning that her experience of time is focused on the thing she seeks rather than time itself. The truism, ‘not to be like cured or anything’ takes on a whole new meaning in that the future contributes to personal meaning. In particular, her sense of what is possible in her life.

In summary, it is true that this chapter explored the inner lives of Audrey, Alexandra, Faustina, Naira, Savannah, and Sonal. It is also true that this was not the sole intention. Researchers are unable to ‘know’ their participants uniquely. Uniquely, perhaps in the way a medical practitioner ‘knows’ his or her patient. A researchers’ subject is not the participant. Rather, the subject is that phenomenon. That is, the experience of being diagnosed with RRMS and the experience of taking DMT. Audrey’s descriptions are an example of these phenomena. So are the experiences borrowed from the other participants. Once borrowed, these experiential accounts are regarded, for all intents and purposes, as epistemologically fictious.

It is hoped that this chapter has constructed an inquiry that made the experience of being diagnosed with RRMS and the experience of taking DMT recognizable to the reader. In this endeavour lies the possibility of becoming more sensitive to the experiences of the participants. What follows next is a focus on linking current findings to previous literature.

Chapter Five

Discussion

This chapter, as is the case with discussion chapters, characterizes what has gone before and consolidates the findings discerned from the experience of a diagnosis of relapsing-remitting multiple sclerosis (RRMS) and the experience of taking disease-modifying treatment (DMT). Within this context, a focus is placed on linking the reported findings to the previous literature. Equal, consideration is given to the discerned themes and their ability to answer each of the two research questions. Next, the chapter will move on to discussing the implications of this thesis. The result of which indicates that research, theory and clinical practice related to people with RRMS (PwRRMS) is best thought of as a dynamic equilibrium where all components weigh in. At this point, the chapter examines the limitations of this thesis. In light of which, a perspective on avenues for future research is outlined. Finally, a concluding statement is presented which is reflective of this thesis marking another step in understanding how PwRRMS experience challenges before, during and after a diagnosis of RRMS.

5.1 Findings related to the First Research Question

The question as to how individual's experience a diagnosis of RRMS must include the associated complexity. According to the reviewed literature, this complexity should fundamentally acknowledge that symptomatology can vary greatly for each individual (*see* Crayton & Rossman, 2006; Newland, et al., 2016) and recognize the multifaceted nature of physical impairment (*see* Burke, 2019; Isakkson & Ahlström, 2006; Pretorius & Joubert, 2014; Toombs, 2001). Both dimensions of which were confirmed by this thesis (*see* 4.2.1.1 Bodily

Interruption and 4.2.1.2 Fatigue). Fatigue, a heavily reported symptom (*see* Capone et al., 2019; Krupp, 2003; Leocani et al., 2008; Newton et al., 2016; Smith et al., 2013; Tur, 2016), was noticeable in many of this thesis' participant narratives. In this respect, the applicable accounts provided a framework to discern the relationship between symptomatology and daily life whilst confirming the unpredictable and complex nature of RRMS. Such understanding equally highlights how the unique experience, presentation, and intensity of symptoms influence psychological well-being.

Within the theme of *Psychological Distress* (*see* 4.2.1.3), it was clear that some participants experienced vulnerability in relation to their symptoms which a diagnosis did not diminish, for a few, the feeling was intensified. It is in this respect, as it was described, that the moment of psychological distress was the moment when participants felt as though the meaning of life had disappeared and they no longer had a place in the world. The literature is clear that the experience of psychological distress is not uncommon as studies have cast a light on how the intricacies of a diagnosis can transform an individual's being-in-the-world and what their world becomes (*see* Al-Sharman et al., 2018; Beshears, 2010; Burke, 2019). Similar to a previous study (*see* Issakson & Alhstrom, 2006), this thesis acknowledged natural human responses, namely, uncertainty, trepidation, and anxiety to unexperienced symptoms until an explanation was obtained. Yet dissimilarly, it is noteworthy to highlight that this thesis discerned what has, as yet been largely unexplored, namely, the nature in which the experience of receiving a diagnosis of RRMS is associated to a 'deep depression' and the need to understand, address, and treat this disorder separately from RRMS. On the one hand, it is worth drawing attention to how this disorder limits an individual's ability to experience wonder, gratitude, and elation for levels of activity they can undertake within the confines of a diagnosis of RRMS. On the other hand, while certain symptoms of depression overlap with those of RRMS, an increased focus is required to identify and establish the appropriate treatment for the former and not interpreting this form of distress as an inevitable consequence of the RRMS progression. It is in this respect that an active treatment approach may be beneficial for improving mood as well as reducing the fatigue associated to both conditions.

Unsurprisingly, there is a vast body of knowledge (*see* Al-Sharman, 2017; Burke, 2019; Malcomson et al., 2008) emphasising how receiving a diagnosis of RRMS resulted in immense emotional turmoil. Indeed, it was evident that for participants in these studies the reality of a diagnosis was fraught with uncertainty owing not least to the unpredictable nature of RRMS. The literature has indicated that common emotional responses varied between *fear* and *devastation* which often changed during and after diagnosis. However, in stark contrast to previous researchers' (*see* Al-Sharman, 2017; Beshears, 2010; Burke, 2019), this thesis' themes of *Diagnosis Inconsistencies* (*see* 4.2.5.1) and *Power Imbalance* (*see* 4.2.2.2) presented an alternative insight into the manner in which some participants experienced diagnosis within the primitive medical enterprise. Although at times this was reflective of an epistemic injustice and at other times suggestive of a disenchanted breakdown in the dialogical relationship, the language of science permeated individual existence so that the experience of the world and of oneself became scientized. It was here that such experiences of a diagnosis of RRMS was compounded by a drastic felt sense of disillusion, helplessness and disbelief.

Diagnosis Inconsistencies (*see* 4.2.5.1) acknowledged the challenges associated to making a diagnosis which has been long recognised and well documented (*see* 1.1.5 Diagnosis). It can be said that some medical practitioners experience difficulty in associating the early symptoms to RRMS, that they may be unaware that a lack of prompt intervention may preclude relapse and/or that postponing an accurate diagnostic could potentially be problematical. It is worth drawing attention to the significance of this matter. *Diagnosis Inconsistencies* in the large part expressed how misdiagnosis increased morbidity, created inadequate treatment plans and may have delayed the treatment of other potentially curable pathologies. From an economic lens, it is important to hold in mind the influence of a misdiagnosis and the treatment of misdiagnosed individuals, especially in developing nations. From a theoretical and clinical lens, although decades of research have culminated in a more rapid diagnosis of RRMS, there remains a need for researchers to model and decipher ways to prevent misdiagnosis. Researchers may be able to fulfil this need by ascertaining whether the McDonald Criteria (2017) is being applied correctly in clinical practice. This would mean exploring whether clinical or previous events are being substantiated by objective corroborative evidence and whether the radiological criteria are being applied appropriately. Equally, in cases of diagnosing difficulty, either a second opinion from a neuro-radiologist would be recommended or a cerebrospinal fluid and serum oligoclonal bands assay could be performed. In essence, attempts should be made to achieve an equilibrium between diagnostic certainty and a timely diagnosis.

Multiple studies (*see* Al-Sharman, 2017; Beshears, 2010; Burke, 2019; Issakson & Alhstrom, 2006; Pretorius & Joubert, 2014; Toombs, 2001), including this one, support the view that for many individuals, a diagnosis of RRMS fosters experiences of uncertainty. However, this thesis was a point of departure from which three original themes, namely, *Guilt* (*see* 4.2.2.1), *Secrecy* (*see* 4.2.3.1), and *Death* (*see* 4.2.4.1) built upon the prevailing nature and degree of uncertainty whilst contributing to answering the first research question. Continuing to examine these three themes has tremendous potential for developing an understanding of the experience of receiving a diagnosis within the continuum of pre- and post-diagnosis.

A complexity associated to the experience of receiving a diagnosis of RRMS was that of death (*see* 4.2.4.1 Death). Within the findings, for some participants, the experience of diagnosis represented the ending of life. That is, diagnosis was a mainspring for conceptualisations of death and the reconfiguration of existence. Surprisingly, there is little, if any literature relating to how this unmitigated challenge, this transcending of the advent of physical death is understood in clinical practice. Therefore, the participant accounts stand as invaluable interpretations which contribute substantially to understanding the packages of care required for individuals who receive a diagnosis of RRMS. It would be of importance for healthcare professionals (HCP) who encounter individuals with suspected or newly diagnosed RRMS to keep in mind that individuals may have incorporated inaccurate conceptualisations of the disease. And so, initial intervention(s) could be based around providing a thorough understanding of the autoimmune disease. What is meant by 'thorough' is a level of understanding that limits PwRRMS engaging in internet searches to find answers. Whilst other studies (*see* Beshears, 2010; Burke, 2019) have reported on the commonality and the experiences of PwRRMS internet searching the prognosis of their condition, it remains important to address any inaccuracies and uncertainties early on as it can influence treatment decision making and treatment compliance.

In a somewhat surprising theme, implicit in the participants accounts, was a reverberating sense of secrecy (*see* 4.2.3.1 Secrecy). The nature of which requires further grounding. Whilst it is pertinent to take note of how symptomology was no longer a private experience of bodily interruption but rather a transition into a medical ontology; the experience of being diagnosed came with the message that participants sought to maintain control over those who knew of the diagnosis. In other words, secrecy did not lock away the experience deeply inside of an individual that she could not see, rather that she is seldom, if ever, in the right position to see it. It is this exposure to, and the at times guilt (*see* 4.2.2.1 Guilt), that encouraged such privacy. Yet, the remarkable thing here is that this realm of secrecy goes one step further by suggesting that PwRRMS engage in a personal attempt to create and maintain a progressive narrative of life in the face of a diagnosis. Alternatively stated, the solitary experience of receiving a diagnosis becomes opaque whilst PwRRMS engage in numerous attempts to find their way back into the normalcy of life. Thus, for some, the experience of receiving a diagnosis is a personal and multifaceted undertaking and not a one-step process.

Within the realm of *Guilt* (*see* 4.2.2.1)*,* the lived experience of receiving a diagnosis of RRMS was not a free-standing individual response, but rather an experience within a specific zone of personal relations. This finding was unlike that reported in previous literature as it was now described by participants when reflecting upon the social experience of the body as an aberration to others and the body no longer being the entity as they experience it. In fact, the value of discerning how participants described living with an unrecognizable body, that is, a body that was dis-abled and the experience of this body as perceived by others bared strongly on how previous literature conceptualised the theme of *Guilt*. Isakkson and Ahlström (2006), in their study of PwMS, captured how guilt in combination to depression, sadness, and shame was understood as the body being an object devoid of subjectivity. This conceptualisation was replicated in a previous study of individuals with a progressive phenotype of MS (*see* Burke, 2019). In addition, previous literature has acknowledged how unfamiliarity amongst caregivers of PwMS gave rise to feelings of guilt (*see* Beshears, 2010, Boeije, et al., 2003; Cheung & Hocking, 2004; Grytten & Maseide, 2005). It is in regard to this divergence that the presented theme of *Guilt* is a matter of significant importance for answering the first research question and making an original contribution to the literature.

5.2 Findings related to the Second Research Question

In attempting to chart PwRRMS experiences of taking DMT, in large part, surrendering control to a medical terminology was not compatible with participants personal narratives of ill-health. Although there remains a difficulty in locating a formal point of occurrence, in the context of the second research question, the theme *Body Object* (*see* 4.3.1.1) provides a useful point of reference. This theme elaborated some ideas about the relationship between the language of nosology and the ontological constitution of being. That said, for all of the participants, their bodies were described as being subjected to reductionist and rational standards which became a source of definition. This strengthened the degree to which personal meanings were structured from health into ill-health, and the degree to which ill-health negotiated life. Researchers (*see* Fawcett & Lucas, 2005; Finlay, 2003) have provided similar findings.

Many studies have sought to provide a framework with which to understand how PwMS attempt to gain control over the unpredictable nature of the disease and the corresponding negotiation of life (*see* Johnson et al., 2006; Lowden et al., 2014; Miller & Jezewski, 2001, 2006; van Capelle et al., 2017; van Reenen et al., 2019). The theme *Decision Dilemma* (*see* 4.3.1.2) discerned the corollary of personal attempts to create an overall self-vitality embodied as a rich matrix of meaning within the world. This process began with deciding on a DMT agent which did not exclusively mean treatment in the sense of a reduction of disease symptoms but rather treatment which maintained a progressive narrative of life. Though personal and socially valued dimensions played a central role in the DMT selection process, many participants described a palpable pain (*see* 4.3.1.3 Pain) engulfed deep within the experimentational and transient experience of taking DMT. That is, some participants were unable to separate themselves from the associated pain experience which captured the fragile dimension of the body. It was this powerlessness that was narrated as an unrelenting compromise of corporeality. Nonetheless, the body was given an identity which provided an opportunity to embrace the body as a mechanism to repair. A mechanism of forging and renewing relationships with life through an altered sense of embodiment.

When it came to renewing relationships with life, a crucial dimension was the perceived influence of the future (*see* 4.3.1.4 Reformulated Life and 4.3.3.1 Future Orientated). Perhaps the most poignant manner in which to describe this dimension is to highlight how DMT impacted RRMS - to the extent that life no longer represented the boundaries of ill-health, but rather a restabilizing process. For many, taking DMT meant enduring the physical strains of a diminished embodiment in the present moment before viewing the open possibilities for a new future. That is, reintegrating temporal experiences, and, concomitantly, experiencing an ability to exist as a center of intentionality capable of a more cohesive sense of personal organization.

Other studies have cited similar findings. For instance, Van Capelle et al. (2017) reported the theme "hope of delaying the progression of the disease" (p.4) as a reference to the increased importance of the future in the DMT selection process. In agreement, van Reenen et al. (2019) reported the theme "living in the now" (p.9) which referred to:

> "certain activities and liberties are lost, and satisfaction needs to be found elsewhere. What has been lost has been replaced by something else, something that might not have been there without having MS: the urge to live in the now and to enjoy life as much as possible and for as long as possible." (p.10).

What this meant is that for PwRRMS, whilst fighting with the uncertainty and unpredictability of an autoimmune disease, DMT represented an inherent meaning. That is, the experience of taking DMT represented a transition into the horizon of the future. A future that structured life according to goals and undertakings. A future that could never erase the experiences and the lost opportunities associated to ill-health but could create its own temporality. Such an active process view could be associated to the following DMT agents; Alemtuzumab (Lemtrada®), Dimethyl Fumarate (Tecfidera®), Ocrelizumab (Ocrevus®) (this thesis), Interferon Beta 1a (Avonex®), Glatiramer Acetate (Copaxone®), Fingolimod (Gilenya®) (van Capelle et al., 2017), and Teriflunomide (Aubagio®) (Van Reenen et al., 2019).

Perhaps the most intriguing finding in specific reference to the second research question is the manner in which PwRRMS combine treatment (*see* 4.3.1.5 Complementary and Alternative Medicine). Within this original theme, a light was cast on taking DMT – a light that was missing within the current body of knowledge. It is worth recognizing that participants often adopted alternative treatment strategies which marked a significant deviation from commonly researched alternative agents of treatment (*see* 1.1.6 Treatment). This does not necessarily denote definitive conclusions regarding interventions. Rather, this speaks volumes about how the continuing mystery regarding MS pathophysiology is interfered from the lived experience of PwRRMS. To the reader, combining DMT and CAM can present as unorthodox. However, effectiveness may be derived from the placebo effect alone and, unless extremely or potentially harmful, such an intervention should not be written-off. Though definite conclusions about this treatment regimen remain premature at present, the combination of treatment discerned various dynamics that are likely to play a role in the treatment selection process. It may well be that PwRRMS combine treatment because the degree of clinical benefit and the optimal dosage of DMT remains uncertain or that there remains much to understand about which process is initial triggered: cyto-degeneration (inside-out) or a primary autoimmune attack (outside-in). Either way, by recognizing and understanding how and why PwRRMS combine DMT and CAM can hopefully enable a better understanding of the components involved in the disease process. For this reason, further investigations are required to consider the relative consistent use of alternative agents as a means for the possibility of prevention, and potentially even the treatment of RRMS (*see* 5.6 Recommendations for Future Research).

5.3 Implications of this research

This thesis has plausible implications for theoretical and empirical research. For instance, the literature related to RRMS and DMT has relied heavily on quantitative approaches of inquiry to arrive at findings subsequently applied to PwRRMS. The findings gleaned from this thesis indicate toward the qualitative method of inquiry being a valuable approach to understanding how DMT agents exert their effect on PwRRMS (*see* 4.3.1.4 Reformulated Life). At various points during the analysis, it was clear that no form of treatment substantially improved the degenerative disease process in RRMS. Although this should come as no surprise, it is worth recognizing that whilst disease heterogeneity will persist in presenting challenges to clinicians treating RRMS, pursuing further phenomenological inquiries would be of merit. The reasons for which are as follows.

The findings of this thesis point to an overarching need to understand the interplay between RRMS and DMT in greater depth. With that said, it may well be that researchers would not have to seek a detailed exploration if PwRRMS could be treated with DMT that was easier to administer and better tolerated. As this is not currently the case, researchers should pay more attention to phenomenological inquiries in order to step closer to identifying treatments that can promote an improved quality of life and ultimately lead to the prevention of neurodegeneration. Advancing these understandings would prove clinically relevant, as the interplay between RRMS and DMT would be more systematically studied.

With respect to this thesis' findings, it is argued that the value of researching the experience of taking DMT has been demonstrated. Whilst Kalb et al. (2015) argue that "the last 20 years have provided a significant number of treatment options that improve prognosis and quality of life for people with MS" (p.39), this thesis has taken this argument further by identifying salient aspects of taking and combining DMT and CAM. Future research in this area should develop these arguments further and to the point that the principles of evidence based DMT practice can be applied to CAM treatment. For instance, Wingerchuk and Carter (2014) understand the widely accepted DMT treatment process as either an escalation or an induction approach. The escalation approach comprises of an initiation of a moderately effective yet highly safe DMT agent and then a change to a DMT agent characterized as highly effective yet exhibiting an increased safety risk in the event of an unsatisfactory response to the former. The induction approach is based on the desire of obtaining a rapid remission of a very active MS. Thus, treatment comprises of an initiation of a highly effective DMT agent for a defined time period after which either observation or a lower risk maintenance treatment is initiated. Whilst both of these approaches are valuable in guiding treatment for PwMS, there remains a paucity of evidence regarding CAM treatment strategies. Perhaps the paucity of such knowledge stems from the complexity associated to investigating the effects of CAM on PwMS and/or the financial commitments involved in unequivocally assessing efficacy. Nonetheless, studies should be undertaken. A way of undertaking such studies is by duplicating this thesis with other samples, including other phenotypes of MS, and attempting to gain a more extensive understanding of CAM usage patterns and decision making. At the same time, of value would be assessing CAM treatments scientifically, even if there remains no methodological and practical consensus.

Whilst the abovementioned implications are valuable to theoretical and empirical research, implications for clinical practice are plausible. In specific reference to the call for an integration of counselling psychology and neuropsychology (*see* Goss, 2015a; 2015b; Rizq, 2007), an introductory step could include a review of the standards for the accreditation of doctoral programmes in counselling psychology to establish whether sufficient training is being provided on neuropsychology. What is meant by 'sufficient' is a minimum level of proficiency as opposed to a fully specialised training – as there is already a pathway for practitioners to become fully qualified as neuropsychologists (*see* the Qualification in Clinical Neuropsychology). This level of proficiency would include a delicate amalgamation of both counselling psychology's blend of scientific, humanistic, and reflective models of working and neuropsychological assessments and psychometrics. It is believed that this blend can generally complement the phenomenological core of counselling psychology practice with the argument also being made that counselling psychologists are well placed to deliver neuropsychological assessments and psychometrics in a relational and reflective manner (*see* Fairfax, 2007).

Another way in which the two disciplines can be brought together is through interdisciplinary research. If counselling psychologists engage in interdisciplinary research with either neuropsychologists and/or neuroscientists what can emerge is a unique integration which develops novel ways to further understand both neurological disorders and psychological distress. Opening the channels of research would not necessarily mean an abandonment of distinctive professional identities or the respective overriding commitment to the practitioner and client relationship. Rather this potentially rich tapestry of shared language, in effect, a recognition of the biopsychosocial model would acknowledge the differing language of each discipline whilst bringing a softer and more approachable set of meaning to neuroscientific findings. Integrating in this way could help counselling psychology continue to move forward as a scientific and empirical field of psychology whilst strengthening the scientist-practitioner element of its identity. Another method of integration could be aligned to the pluralistic framework as proposed by Cooper and McLeod (2011).

Based upon the light cast on the experience of receiving a diagnosis of RRMS and taking DMT – a light that was missing within the current body of literature - it is worth recognizing that these implications which once taken into consideration can be advantageous to the packages of care for PwRRMS. For instance, clinicians should strive to develop a holistic understanding of PwRRMS due to the unique pathogenesis in each individual (*see* 4.2.1.1 Bodily Interruption). Equally, whilst thinking about treatment regimen and treatment compliance which can be based on a diverse range of unique psychological, biological, and social elements, it seems reasonable for clinicians to deliberate the experiences discerned from this thesis and to collaborate in the treatment decision making process especially when in reference to CAM.

With this in mind, it would be essential for practice to be based on an evidence base specific to the RRMS population. A simple Google Scholar search of 'CAM' and 'RRMS' yields 8,780 results which indicates toward a degree of intrigue in CAM treatment options for the RRMS population. Yet, due to studies of CAM treatment being confounded by challenges, namely, small participant samples, reverse causality, complications in quantifying endpoints and an absence of an appropriate biomarker of improvement, drawing meaningful treatment efficacy conclusions can be difficult. And so, in the interim as high-quality evidence is developed, clinicians should acknowledge the contemplation of CAM use as representing an interrelationship between the mind, body, and soul and as an indication toward a low level of trust in the effectiveness of taking DMT. It may well be that DMT agents can be highly effective, but they are not panaceas.

It is worth recognizing that clinical practice may well benefit from patient–clinician discussions and recommendations surrounding CAM treatment. This collaboration would be based on PwRRMS expressing an interest in complementary treatment or informing of complementary treatment use to clinicians which studies (*see* Apel-Neu & Zettl, 2008; Pucci et al., 2003; Schwarz et al., 2008; Stoll et al., 2012) including this one, found does not often happen. However, it is imperative that these discussions take place with the reasons being as follow. Efforts to discuss, educate and inform should begin by allowing adequate time and adjusting content to the needs of each PwRRMS. Perhaps most importantly, the need for this implication stems from the need to exercise appropriate levels of clinical vigilance for those who seek alternative strategies to manage the disease holistically. On a similar line, the frequency of use clearly warrants discussions around the safety and possible complications of CAM use in combination with DMT. In addition, the belief that CAM treatment is harmless should not be ignored. As per this thesis findings, the nature of the collaboration being proposed could potentially overcome the disagreements often experienced within the primitive medical enterprise (*see* 4.2.2.2 Power Imbalance and 4.3.1.2 Decision Dilemma). This is very much consistent with the attempts that should be made to intensify efforts to understand the prevalence of CAM use and CAM treatment not only to enable clinicians to be up-to-date, open minded, and clinically cautious when making decisions pertaining to DMT and CAM treatment. But to also collaborate with PwRRMS in making informed choices regarding the multi-dimensional elements of their healthcare.

5.4 Limitations of this research

Two distinct limitations can be attributed to this inquiry. Firstly, given that the recruited sample consisted of females solely, the recruitment of males could have discerned themes other than those presented. Although this thesis has highlighted the female preponderance in MS (*see*

1.1.3 Prevalence and Epidemiology), future researchers may overcome this limitation by taking cognisance of this thesis recruitment methods whilst exploring other recruitment avenues. Such as, recruiting collaboratively with third parties (i.e., MS societies and/or neurological hospitals) or directly recruiting members of MS societies. Secondly, the inclusion criterion extended to any individual who had received a diagnosis of RRMS which meant that the time frame between the day of the diagnosis and the day of the interview in some cases was several years (*see* 3.6.4 Participants). This can be regarded as a limitation because given that the participant narratives were generated retrospectively, those narratives may have been affected by the participants' ability to accurately recollect experiences. This may be of particular pertinence given the cognitive impairment associated with MS (*see* 1.1.2 Pathophysiology, Symptoms and Classifications). A way of future studies overcoming this limitation is by adding to the inclusion criteria the requirement of potential participants scoring suitably on either the Screening Examination for Cognitive Impairment (Beatty, et al., 1995), the Mini Mental State Examination (Cockrell, et al., 2002), or the MS Neuropsychological Screening Questionnaire (Nauta, et al., 2019). Equally, with these two limitations in mind, the reported themes may not be transferable to PwRRMS who are at a different stage of the RRMS disease course.

5.5 Recommendations for future research

A core question raised (*see* 5.2 Findings related to the Second Research Question) is whether it is possible to improve treatment outcomes for PwRRMS by integrating DMT and CAM treatment. To facilitate clarity, this thesis supports the utilisation of CAM. Such support is built on the foundation that a proportion of participants from this inquiry used CAM at least once during their journey with the disease. For this reason, an answer to the question of attitudes toward CAM is that PwRRMS generally do consider alternative forms of treatment. Within such a consideration lies the view that the healing process is not just a passive response to

RRMS and the opinions of medical professionals but rather is a dynamic, active, and autonomous process. With this in mind, researching different combinations of DMT and CAM should be considered to assess the real value of an integrated approach for the treatment of RRMS. This line of inquiry may also enhance insights into those who commence DMT and then either stop, switch, or supplement their treatment regimen which may guide future packages of care.

Notwithstanding the abovementioned limitations, researchers should take cognisance of this inquiry and explore the following avenue as it can be a fruitful path for future research. A uniqueness of this thesis is that it has taken a preliminary stride in discerning the experience of taking different DMT agents in a single inquiry. With this in mind, the inquiry has shown that not only is this approach underused but the experience of RRMS affecting DMT decision making requires further attention. Thus, replicating this inquiry with samples stratified by gender, ethnicity, and geographic location may contribute valuable insights and further illuminate the meaning of the phenomenon. It is in this respect that this line of research can be enhanced further by either repeating semi-structured interviews through a longitudinal study design or by augmenting subjective accounts in combination to objective measurements to yield further knowledge.

Finally, a note on reporting. As discussed (*see* 2.0 Literature Review), past researchers have not clearly reported the recruited participant(s) phenotype of MS. Therefore, moving forward for the purposes of accuracy, it is important that all future studies clearly state the recruited participants phenotype of MS as it will prevent findings being perceived as generalisable across all of the phenotypes of MS.

5.6 Final Thoughts

By no means does this thesis claim to comprehensively address the identified gap in the body of knowledge. It does, however, confirm that individuals experience a variety of challenges before, during and after a diagnosis of RRMS and provides a progressive step in understanding why PwRRMS supplement DMT with CAM treatment. Whilst previous investigations into this latter phenomenon have tended to focus on the efficacy of the respective forms of treatment, it has been suggested herein that due to the complex nature of RRMS, treatment decision making is challenging and multifaceted. With this in mind, will this inquiry transform the current methods of treating RRMS? Most likely not in the short term. Primarily due to the role of CAM in the treatment of RRMS yet to be substantiated. However, over the longer term, and in the context of the growing popularity of taking CAM, there may well be more emphasis placed on combining DMT and CAM treatment within the current continuum of packages of care.

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APPENDIX 1

RECRUITMENT POSTER

DO YOU HAVE A DIAGNOSIS OF RELAPSING-REMITTING MULTIPLE SCLEROSIS?

IF SO, HAVE YOU EXPERIENCED DISEASE-MODIFYING TREATMENT?

- In the context of this research, the diagnosis of relapsing-remitting multiple sclerosis is characterised by periods of marked symptom exacerbations and/or remission and full recovery between relapses.
- Suitable participants will have taken disease-modifying treatment (DMT).

This study explores how individuals with relapsing-remitting multiple-sclerosis experience disease-modifying treatment.

Your participation would involve a single face-to-face interview with myself, which would take place at a convenient time and place for you. The interview will last approximately 45 to 90 minutes and will be audio recorded. Any material that may potentially aid identification will be removed.

For more information about this study, or to volunteer, please contact: Dipesh Patel - Counselling Psychologist-in-Trainng at u1530577@uel.ac.uk

APPENDIX 2

PARTICIPANT INFORMATION SHEET

Principal Investigator: Dipesh Patel / u1530577@uel.ac.uk

You are being invited to participate in a study, the objective of which is to explore how individuals experience a diagnosis of relapsing-remitting multiple-sclerosis and how individuals experience taking disease-modifying-treatment. This study will constitute the research component of the Professional Doctorate in Counselling Psychology at the University of East London. Before you agree to take part in this study, it is important for you to understand what your participation will involve.

What Is the Purpose of The Study?

The purpose of the proposed study is to contribute to the existing knowledge base pertaining to relapsing-remitting multiple-sclerosis (RRMS) and disease-modifying-treatment within the domain of Counselling Psychology. In order to do so, the enquiry process will be orientated towards exploring, describing, and understanding the holistic lived experience of taking disease-modifying-treatment for those with RRMS and the meaning ascribed to this experience. By focusing on the third level subjective experience, the study will aim to capture this experience in terms of understanding the underlying impairments of being diagnosed with RRMS and the influence of disease-modifying-treatment. Finally, by exploring the lived experience of RRMS and disease-modifying-treatment, it is hoped that the exploration will gravitate toward understanding RRMS and disease-modifying-treatment, the merits of this intervention, and whether it is possible to deliver better packages of care.

Why Have I Been Invited?

Between five and six individuals will be invited to take part in the study. You have been invited because you have experienced being diagnosed with relapsing-remitting multiple sclerosis and have taken disease-modifying-treatment. You are eligible to take part in this study if you, in addition to the mentioned criteria, are eighteen and over.

Is It Mandatory To Take Part?

Participation in this study is completely voluntary. If you decide you would like to take part in this study, you will be asked to sign a consent form prior to your participation. You may withdraw your consent to have your interview material included in this study by informing the researcher of your decision within a three-week window from the time of the interview. Should you withdraw, the researcher will not use your anonymised data in the write-up of the study or in any further analysis that may be conducted by the researcher. You may decline to answer any questions you are asked, take a break during the interview or decide to stop it completely at any point without detrimental affect

What Will the Interview Consist of?

The interview will consist of a single audio recorded one-to-one interview and will last approximately 45 to 90 minutes.

What Are the Risks?

As a participant, it is important that you are aware of the possible risks associated with your involvement in the study. Given the nature of the study (i.e., a reflective process) you may re-evaluate yourself and your experience of being diagnosed with relapsing remitting multiple sclerosis or your experience of taking disease-modifying-treatment. With this in mind, it is important that you take time to consider the potential implications of your participation in this study before you agree to take part. Steps have been put into place to prevent/minimise implications from occurring. For instance, in recognition of the potential psychological discomfort participation in this study may cause, at the end of the interview you will be fully debriefed. This will give you the opportunity to ask questions and/or discuss concerns you may have. Equally, you will be provided with a list of relevant sources of support, which you can call upon should you experience distress as a result of your participation. If you have any other concerns regarding risks, please do not hesitate to ask.

Will My Data Be Confidential?

The personal information you provide on the researcher's copy of the Informed Consent form will not be duplicated elsewhere and will remain stored in a secure setting in accordance with the Data Protection Act 1998, seen only by the researcher. Your name will not appear in any report or publication resulting from this study. Your name and contact details will be stored on an encrypted USB device and will be known only to the researcher. Once your interview has been completed the audio recording will be transferred onto an encrypted USB device, which is accessed with a password known only to the researcher. The interview will then be deleted from the audio recording device. The audio file of your interview, the electric copy of your interview transcript and researcher's copy of your Informed Consent Form will all be stored separately in secure settings in accordance with the Data Protection Act 1998. They will be available to only the researcher and to his supervisor and the Counselling Psychology Doctorate research dissertation examiners at their request. Only material from the research interviews will be used in this study. In accordance with the BPS Code of Conduct & Ethics (2009) should you disclose any intended or actual risk of serious harm, this would constitute an exception to the agreed confidentiality.

This study will be assessed and may potentially be published. With this in mind, one year after the study has been marked and the results have been ratified; (i) the audio recording of the interview will be destroyed, (ii) the informed consent form will be destroyed, and (iii) the electronic copy of the interview transcript and the researcher notes will be destroyed.

Further Information and Contact Details

If you have any questions or concerns about how the study has been conducted, please feel free to ask any questions or alternatively, please do not hesitate to contact the study's supervisor:

Dr Martin Willis
School of Psychology
University of East London
Water Lane
London, E15 4LZ
Tel: 020 8223 4492
Email: M.Willis@uel.ac.uk

Or the Chair of the School of Psychology Research Ethics Sub-committee:

Dr Tim Lomas
School of Psychology
University of East London
Water Lane
London, E15 4LZ.
Tel: 020 8223 4465
Email: t.lomas@uel.ac.uk

Thank you in anticipation.

Yours Sincerely,

Dipesh Patel

Counselling Psychologist-In-Training

u1530577@uel.ac.uk

APPENDIX 3

INFORMED CONSENT

Principal Investigator: Dipesh Patel / u1530577@uel.ac.uk

I have read the information presented about the research study being conducted by Dipesh Patel, Counselling Psychologist-in-Training and student of the University of East London. I have been given the opportunity to ask any questions and express any concerns relating to my involvement as a participant in this study. I am satisfied with the responses I received.

I am aware my interview will be audio recorded and understand that anonymised excerpts from my transcribed interview may be included in his Counselling Psychology Doctorate research thesis.

I have been informed of the limits of confidentiality of this study and the extent to which this research may be available to the public.

I understand I can withdraw my consent to take part in this study at any time. I understand that should I choose to withdraw the researcher reserves the right to use my anonymised data in the write-up of the study and any further analysis that may be conducted by the researcher.

This study has been reviewed by and received ethical clearance through the University of East London Ethics Committee. I have been informed that if I have any questions or concerns resulting from my participation in this study I can contact the researcher, Dipesh Patel, u1530577@uel.ac.uk, and/or the research supervisor, Dr Martin Willis, M.Willis@uel.ac.uk by email directly.

With complete consent, I agree to participate in this study, of my own free will.
YES / NO

I agree to have my interview audio recorded.
YES / NO

I agree to the use of anonymous excerpts in the Counselling Psychology Doctorate research dissertation.

YES / NO

Participant's Name:

____

Participant's Signature:

____

Date:

____

Researcher's Name:

____

Researcher's Signature:

____

Date:

____

APPENDIX 4

DEBRIEF INFORMATION SHEET

Principal Investigator: Dipesh Patel / u1530577@uel.ac.uk

Thank You for participating in this study. As stated in the Participant Information Sheet, the purpose of this study is to explore individual experiences of being diagnosed with relapsing-remitting multiple-sclerosis and individual experiences of taking disease-modifying-treatment.

Please note that the Participant Information Sheet outlines how this study works in accordance with the Data Protection Act 1998. Equally, if only to aid and remind, you may withdraw your consent to have your interview material included in this study by informing me of your decision within a three-week window from the time of the interview. Should you withdraw, I will not use your anonymised data in the write-up of the study or in any further analysis that may be conducted by myself.

For your convenience, I have supplied suggested support services available to you should you require them as a result of your participation in this research study:

Multiple Sclerosis Helpline
Website: www.mssociety.org.uk/care-and-support/ms-helpline
Email: helpline@mssociety.org.uk
Phone: 0808 800 8000

Multiple Sclerosis Society
Website: www.ssociety.org.uk
Email: helpline@mssociety.org.uk
Phone: 0808 800 8000

Local Multiple Sclerosis Services
Website: www.mstrust.org.uk/about-ms/ms-services-near-me
Email: info@mstrust.org.uk
Phone: 0800 032 3839

If you have any questions and/or concerns about how this research has been conducted, please contact Dr Martin Willis by email *M.Willis@uel.ac.uk* or by post at The Department of *Psychology, University of East London, Stratford Campus, Water Lane, London E15 4LZ.*

Please sign below as an indication of your acknowledgement the research interview was carried out in an ethical and professional manner.

Thank you again for your participation and co-operation.

Dipesh Patel

Counselling Psychologist-in-Training

u1530577@uel.ac.uk

Participant's Name:

____

Participant's Signature:

____

Date:

____

APPENDIX 5

NOTICE OF ETHICS REVIEW DECISION

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER: Elley Wakui

SUPERVISOR: Martin Willis

STUDENT: Dipesh Patel

Course: Professional Doctorate in Counselling Psychology

Title of proposed study: An Interpretative Phenomenological Study Exploring Individuals' with Relapsing-Remitting Multiple-Sclerosis Experiences of In-Patient Neuropsychological Rehabilitation

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above-named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The

revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

Approved

Minor amendments required *(for reviewer)*:

The phrasing of the right to withdrawal is a little confusing in the consent and debrief –it reads a little as though even if the participant withdraws consent to use the data, the researcher can still do so? Perhaps it just means that after the time window of 3 weeks, that the anonymised data can still be used?

Major amendments required *(for reviewer):*

Confirmation of making the above minor amendments *(for students)*:

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *(Typed name to act as signature):*	DIPESH PATEL
Student number:	u1530577
Date:	28/05/2019

(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

YES

Please request resubmission with an adequate risk assessment

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

/ HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

/ MEDIUM (Please approve but with appropriate recommendations)

/ x LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Typed name to act as signature)*: Elley Wakui
Date: 28/05/2019

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

RESEARCHER PLEASE NOTE:

For the researcher and participants involved in the abovenamed study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

UNIVERSITY OF EAST LONDON

School of Psychology

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology.
Note that approval must be given for significant change to research procedure that impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Tim Lomas (Chair of the School Research Ethics Committee. t.lomas@uel.ac.uk).

HOW TO COMPLETE & SUBMIT THE REQUEST

1. Complete the request form electronically and accurately.
2. Type your name in the 'student's signature' section (page 2).
3. When submitting this request form, ensure that all necessary documents are attached (see below).
4. Using your UEL email address, email the completed request form along with associated documents to: Dr Tim Lomas at t.lomas@uel.ac.uk
5. Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
6. Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

REQUIRED DOCUMENTS

1. A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.
2. Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.
3. A copy of the approval of your initial ethics application.

Name of applicant: Dipesh Patel **Programme of study**: Professional Doctorate in Counselling Psychology **Title of research**: An Interpretative Phenomenological Study Exploring Individuals' with Relapsing-Remitting Multiple-Sclerosis Experiences of In-Patient Neuropsychological Rehabilitation **Name of supervisor**: Dr Martin Willis

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale
In addition to face to face in person interviews in a private session, the proposed amendment would allow participants the option to have an online interview through a safe platform (i.e., Skype)	Given that fatigue can be a common symptom in all forms of multiple sclerosis, the rationale stems from allowing participation in the study through the comfort of the participants own home/safe space. Given the symptoms in mind, the proposed the one-to-one semi-structured interviews (either in person or online) will provide space and flexibility but also the interview questions will be selected economically to accommodate the participant population. The proposed amendment will also adhere to Smith (2009) who suggested that an interview schedule for an articulated adult lasting between 45 to 90 minutes in duration and containing between six and ten open questions along with prompts. With the participant population in mind, a flexible schedule with less but non-directive and open-ended questions will be adopted, lasting up to sixty minutes.

Please tick	**YES**	**NO**
Is your supervisor aware of your proposed amendment(s) and agree to them?	X	

Student's signature (please type your name): DIPESH PATEL

Date: 04/09/2019

TO BE COMPLETED BY REVIEWER		
Amendment(s) approved	YES	
Comments		

Reviewer: Tim Lomas
Date: 4.9.19

UNIVERSITY OF EAST LONDON

School of Psychology

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology.
Note that approval must be given for significant change to research procedure that impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Tim Lomas (Chair of the School Research Ethics Committee. t.lomas@uel.ac.uk).

HOW TO COMPLETE & SUBMIT THE REQUEST

1. Complete the request form electronically and accurately.
2. Type your name in the 'student's signature' section (page 2).
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4. Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
5. Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

REQUIRED DOCUMENTS

6. A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.
7. Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.
8. A copy of the approval of your initial ethics application.

Name of applicant: Dipesh Patel

Programme of study: Professional Doctorate in Counselling Psychology

Title of research: An Interpretative Phenomenological Study Exploring Individuals' with Relapsing-Remitting Multiple-Sclerosis Experiences of In-Patient Neuropsychological Rehabilitation

Name of supervisor: Dr Martin Willis

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale
I would like to propose an amendment to the title of my research. The amendment would see the title *change from*: An Interpretative Phenomenological Study Exploring Individuals' with Relapsing-Remitting Multiple-Sclerosis Experiences of In-Patient Neuropsychological Rehabilitation *to*: An Interpretative Phenomenological Study Exploring Individuals' with Relapsing-Remitting Multiple-Sclerosis Experiences of Disease-Modifying-Treatment	Participant recruitment for the original research title has proven to be challenging. As such, I have been unable to recruit a sufficient number of participants. The challenges have stemmed from potential participants a) not meeting the in-patient neuropsychological rehabilitation criteria, b) differences in type of neuropsychological rehabilitation, and c) on-going treatment from the neuropsychological rehabilitation team. As a result, I have been unable to recruit any participants for my research. In addition to this reason, my decision to request an amendment stems from seeking to increase my opportunities for participation recruitment whilst remaining congruent to the aim of facilitating an understanding of those that experience relapsing-remitting multiple-

	sclerosis. Should this request be approved, I would be able to grant the seven participants that have shown an interest in the research to participate.

Please tick	**YES**	**NO**
Is your supervisor aware of your proposed amendment(s) and agree to them?	x	

Student's signature (please type your name): DIPESH PATEL
Date: 15/10/2019

TO BE COMPLETED BY REVIEWER		
Amendment(s) approved	YES	
Comments		

Reviewer: Tim Lomas

Date: 16.10.19

UNIVERSITY OF EAST LONDON

School of Psychology

REQUEST FOR TITLE CHANGE TO AN ETHICS APPLICATION

FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

Please complete this form if you are requesting approval for proposed title change to an ethics application that has been approved by the School of Psychology.

By applying for a change of title request you confirm that in doing so the process by which you have collected your data/conducted your research has not changed or deviated from your original ethics approval. If either of these have changed then you are required to complete an Ethics Amendments Form.

HOW TO COMPLETE & SUBMIT THE REQUEST

1. Complete the request form electronically and accurately.
2. Type your name in the 'student's signature' section (page 2).
3. Using your UEL email address, email the completed request form along with associated documents to: Psychology.Ethics@uel.ac.uk
4. Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.

REQUIRED DOCUMENTS

1. A copy of the approval of your initial ethics application.

Name of applicant:	Dipesh Patel
Programme of study:	Professional Doctorate in Counselling Psychology
Name of supervisor:	Dr Martin Willis

Briefly outline the nature of your proposed title change in the boxes below

Proposed amendment	Rationale
I would like to propose an amendment to the title of my research. The amendment would see the title *change from*:	Having consulted the literature, I have found hermeneutic interpretive phenomenology to be more phenomenologically oriented than

An Interpretative Phenomenological Study Exploring Individuals' with Relapsing-Remitting Multiple-Sclerosis Experiences of Disease-Modifying-Treatment *To:* Experiences of Relapsing Remitting Multiple Sclerosis and Disease Modifying Treatment: *A phenomenological inquiry*	interpretive phenomenological analysis. And so, this change (informed by Max van Manen's work) would work better in terms of meeting the objectives of my thesis.

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and agree to them?	x	
Does your change of title impact the process of how you collected your data/conducted your research?		x

Student's signature (please type your name): DIPESH PATEL
Date: 31/10/2020

TO BE COMPLETED BY REVIEWER

ResearchUEL
Tue 10/11/2020 12:23
To: Dipesh PATEL

ResearchUEL

Change project title - Mr Dipesh Patel

The Psychology Research Degrees Sub-Committee on behalf of the Impact and Innovation Committee has considered your request. The decision is:

Approved

Your new thesis title is confirmed as follows:

Old thesis title: How do individuals with relapsing-remitting multiple-sclerosis (RRMS) experience in-patient neuropsychological rehabilitation (NR): An Interpretative Phenomenological Analysis

New thesis title: Experiences of Relapsing Remitting Multiple Sclerosis and Disease Modifying Treatment: A phenomenological inquiry

Your registration period remains unchanged.

APPENDIX 6

INTERVIEW SCHEDULE

REMEMBER TO ASK THE PARTICIPANT TO PLEASE REFRAIN FROM REVEALING DETAILS IN THE INTERVIEW, WHICH COULD LEAD TO THE IDENTIFICATION OF A THIRD PARTY, FOR EXAMPLE THE NAME OF THE SERVICE OR ANOTHER IN-PATIENT.

1. Can we start by talking about your relapsing-remitting multiple-sclerosis? Please tell me about being diagnosed and your experience of coming to terms with the condition?

- When were you first diagnosed?
- What do you understand about relapsing-remitting multiple sclerosis?
- What are your symptoms?
- How do you manage your condition?
- Please give some examples of the different managing strategies you use, and in what way they are helpful?

2. How has relapsing-remitting multiple-sclerosis impacted your life?

- How did this feel for you at the beginning? ... What about now?
- How has relapsing-remitting multiple-sclerosis impacted those around you?
- What other changes have happened in your life, as a result of your relapsing-remitting multiple sclerosis?

3. Can you tell me about your understanding of disease-modifying-treatment (DMTs)?

- What you think DMTs are designed to do?
- How do you think DMTs benefit an individual with relapsing-remitting multiple-sclerosis?
- What kind of DMTs were you prescribed? What are your thoughts on these?

4. Can you tell me about your experience using DMTs?

- Can you describe your experience of using DMT?
- What things could you do before and/or after DMT?
- Can you tell me anything about your experience that has been successful and/or difficult?

5. What impact did taking DMTs have upon you and your recovery from relapsing-remitting multiple-sclerosis?

- Have you been able to explore the impact of living with relapsing-remitting multiple-sclerosis?
- Has DMTs allowed you to managing relapsing-relapsing multiple differently? i.e. memory, attention, and planning and organisation; to help in coping with anxiety and depression?
- Can you give me some actual examples (based on your experience)?

6. Can you tell me about how you feel about your experience?

- Having taken DMTs, what elements of the treatment supported you most?
- Describe your thoughts on the value of taking DMTs?
- Please can you give me some examples of things that have happened, which illustrate changes.
- What do you feel has been the most challenging experience for you?
- How are you approaching these challenges?
- How do you see yourself in the future?
- How is this different to how you viewed your future before taking DMTs?
- How have you coped whilst taking DMTs?

7. What would you say to an individual with relapsing-remitting multiple-sclerosis who is about to commence disease modifying treatment?

Thank you for agreeing to take part in this interview, is there anything you would like to add before we finish the interview? Anything I have missed which you feel is important? Any Questions?

APPENDIX 7

ANALYSED PARTICIPANT TRANSCRIPT EXAMPLE

Existential Element	Transcript (Excerpt commences at line 51 of the full transcript)	Commentary
Temporality	I've spent years researching it, trying to understand it. At the time I was like twenty-two	*x] Context of Life Stage*
	and I was like, 'you're telling me that my prognosis is bad?' He said things like, 'if I was	*x] Transition from suffering and solitude toward death.*
Relationality	your sister, this is what I would tell you to do.' And I was just like, 'what do you mean if	
	I was your sister?' 'What is this crap?' Like it was so unprofessional. And I remember	
Temporality	leaving and just sitting in the car and I was like 'I'm going to die.' (.) 'I'm going to die.' (.)	*x] Diagnosis means a threat to life itself.*
	I called my now husband and I just said, 'this is the situation, if you want to go, you can	*x] Diagnosis is the end of her time.*
Relationality	go.' (CRYING) And I don't think he really understood at the time, but he was like 'don't	*x] Diagnosis appears to be the extinction of the self and the final experience of self-awareness.*
	be stupid, we will deal with it as it comes.' And it was just like really bad time for a really	
Temporality	long time. Like for six months, I wouldn't really leave the house. I was really scared. And,	*x] The moment of diagnosis sets limits to her existence. Perhaps also to confound this inevitable vicissitude of time, she is no longer be able to be able (i.e., she brings to an abrupt end her intimate relationship).*
Relationality	even going to the supermarket I had to like really to psyche myself up - like it was just	
	terrifying. Really terrifying. All the stimuli merged into one. So, I couldn't like make sense	
Corporeality	of sound and movement and vision all at the same time. It was like so confusing. It was	*x] How can we make sense of death and diagnosis here? It seems as though death does not happen to those who die, but to those who grieve. Link to Heidegger who suggested human being-in-the-world is always a being-toward-death.*
	just too much. My fatigue was so bad. I was just exhausted all the time. My sisters used to	
Relationality	have to like to make me leave the house and make me shower. Like, I remember like I got	
Relationality	diagnosed early December. I had to go to A&E and they just stuck me in a neuro ward,	
Relationality Temporality	and I remember that like I just want to be alone. And I was really scared.	*x] In the lived experience of receiving a diagnosis, it serves as a backdrop to death.*

APPENDIX 8

PARTICIPANT TRANSCRIPT EXAMPLE

Transcription convention

(.)	Short pause
(...)	Long pause (more than 3 seconds)
[. . .]	Material omitted to ensure confidentiality and/or text extracted due to poor quality of recording.

Transcript

Dipesh: Can we start by talking about your relapsing remitting multiple sclerosis, can you tell me about being diagnosed and your experience of coming to terms with the condition?

Alexandra: OK, so I had my first known relapse, erm in 2015, January 2015 it was in my right eye. At the time I went to um an A&E department in London. Um that specialize in eyes and they had said that it could potentially be MS but given that I was experiencing a viral, signs of a viral infection at the time and was under some stress at work, they suggested, also suggested that it could have been the symptom or the outcome of a viral infection. So, where I was very physically fit. I was very active. I just completely dismissed the idea of having MS. And actually, refused having an MRI scan at the time. I was young and dumb; I like to tell people. I was very naive. So anyway, I went away, and my optic neuritis cleared up within about a month. Two years later. I had Botox injections to my forehead which is something that I do for cosmetic reasons and the following day I woke up with double vision, so my initial instinct was that it was my double vision was caused by the Botox, but again, I went back to the eye hospital and was offered an MRI and at this point I took it. My journey to diagnosis was actually quite complicated because at the time I was told that the MRI scan was clear. That there was no abnormalities on my brain and that potentially my vision problems, although they were unusual could have been explained either by my viral infection two years prior or the Botox at that point. And then six months later, the hospital wrote to me to say that they've made a mistake and actually there were lesions on my brain and that I should return for a diagnosis of MS. So, I did return, and I asked for a second MRI because I wasn't confident in the original findings and because of the issues. And I was given a second MRI in August 2018, which did confirm new lesions within time and space. But within the time frame of me waiting, having the initial, so I went back between June and from June to August, I think I was in an emotional turmoil. Uhm, the thing is, I only knew one person with MS in my life and that was the mother of a friend of mine and she is bed bound and she cannot speak. So, the only exposure that I had to this condition was quite a severe case, so I think emotionally I was catastrophizing. It's difficult. When you're physically fit being told that you've got this condition, and this is the potential outcome. Uhm, when I think I'm someone I don't know if this applies to a lot of people. But I'm someone, I'm a control freak just generally. I plan my life, I sort of say “OK, I want to be married by the time I am this age. I want to have children by this age. I want to have this amount of children and a lot of my plans and now, in my mind, unachievable or I’ve kind of changed, I've had to change my outlook on life and live more in the moment and I think stop taking time for granted, and for granted. So that's, I think emotionally it's been tough. It's been much more harder than that. I mean, I had really serious low’s and I think the way that I kind of dealt with it was akin to the grieving process so there was that lots of stages that I went through where I finally got to a stage of acceptance, but it took me awhile to get there, but sorry am I talking too much?

Dipesh: No not at all. It’s fine.

Alexandra: OK.

Dipesh: Can I just ask you a couple of questions? Do you remember roughly when you were diagnosed with MS?

Alexandra: That would have been in Aug 2018, so after I had my technically my second MRI scan, I went into the hospital around that time for a follow up appointment and was diagnosed then with relapsing remitting MS.

Dipesh: And what were your symptoms at the time? You mentioned the double vision? Did you notice anything else?

Alexandra: So, from, I had to double vision which was in June 2017 bearing in mind there was quite some time from then to my official diagnosis because of the error at the hospital but when they wrote to me to say that they've made the mistake and invited me back in, I didn't go back in until June 2018 and then from June to August when I was waiting for my MRI scan, I did experience a third relapse which was numbness and tingling in my left leg. I speculated with my consultant that maybe the stress of the shock diagnosis brought on this 3rd relapse because the stress of a diagnosis, in some cases can bring on another relapse for MS patients. Especially because it was something that I kind of put to bed and I wasn't expecting to hear any more on the issue and then to get a letter out of the blue, particularly because it was a stressful time in life for me anyway because I received a letter in May 2018, and it was the same time that I bought my first home. So, my speculation is that where I had applied for critical illness and life insurance and given the insurance company permission to contact the hospitals. I kind of speculated maybe that's what kind of uncovered the mistake. Maybe that’s why it triggered the hospital to look at my case records again and then write to me but that is simply my speculation.

I've got obviously no proof of that. So, you can imagine first time homeowner, my place needed a lot of renovation and a lot of which are going to do myself and then I'm diagnosed with MS Uhm. You know, you are kind of life gets turned upside down. So yeah.

Dipesh: One of the next questions is about the impact. You mentioned your life got turned upside down. But before we go into that bit and the second question, I wanted to ask you if you knew much about multiple sclerosis or even relapsing-remitting multiple sclerosis?

Alexandra: Not really. I mean, I'd had, as I say, I had a friend of mine whose mom, she's got a secondary progressive MS, but I didn't know the distinction. I only know the distinctions between the different types of a MS now, so I just knew multiple sclerosis is something that was disabling I've met. In my line of work, I deal with members of the public on a day to day. I have a caseload of my own. I've got clients of my own and I deal with their families at times, so I've met people with MS and kind of know of them having MS but not understanding what impact that had on their life or what their symptoms were. So really and truly, my one, my main source or my main example was my friend’s mother, who as I say is unfortunately quite badly affected by the disease.

Dipesh: And how are you managing your condition?

Alexandra: Before I was diagnosed?

Dipesh: Once you are diagnosed and your initial treatment?

Alexandra: Well before I was diagnosed, I didn't know so I guess I was just managing fatigue and whatever symptoms I had. Like everybody else like drinking coffee and just taking it on the chin like British people do (LAUGHTER). We all say we are tired all the time, so you know when you're feeling tired and everybody else is feeling tired, they think you are normal but when I was diagnosed from June so let’s say, I went back to the hospital in June 2018, was provisionally told I had MS, but I didn't accept the diagnosis until I had my second MRI scan in August 2018. And when I went back and I was officially diagnosed, I had already done some research so what I had done was looked at the available DMT's and I was adamant that I was going to have Lemtrada. I didn't want anything else so when I went to my follow up appointment in August. I said to my consultant that is what I wanted and thankfully, he agreed, and this was before the EMA warning came in, so I was very lucky to be given Lemtrada as a first line therapy. So, I didn't have Lemtrada until November 2018, so there was a couple of months in between August and November where I knew I had MS and I wasn't being treated, but what I did take was a high dose of vitamin D's. So, I take 20,000 units of Vitamin D a day. So, going back to me being a control freak as you can see. I've done my own research and I've looked at what alternative therapies are also good for MS so not just I'm not just treating myself medically but also looking at vitamins and also diet and lifestyle. So, I've now gone vegan, but prior, I only recently became vegan about month ago, but prior to that I went on the keto diet, which I started almost instinctively after I was diagnosed. Sorry excuse me. But not keto that includes dairy basically I was paleo keto so dairy free gluten free. All the free from’s, I adopted (LAUGHTER). So, yeah, I've tried to treat this holistically. Holistically that’s how I’ve tried to manage it.

Dipesh: The second question was around how relapsing remitting multiple sclerosis impacted your life? So, you touched upon at that time buying a new property and your property needing a lot of regeneration work also, but I was wondering if we could unpack that a little bit more?

Alexandra: Well, if I think back, um because now I've had Lemtrada. Sorry. Let me let me rephrase this, if I think back to before I was diagnosed. I was in hindsight, quite clearly unwell. Um in the sense that I was very fatigued, and I was very weak, you know in mind and body I would say. But I didn't know any different so, as I’ve given you example where I would go to work, and people would ask me ‘how are you this morning?’ And I'd ‘say you know what, I'm so exhausted’. And where the next person you know sat next to me would say exactly the same thing ‘oh yeah me too, I didn’t get any sleep last night, kids kept me up’. I just assumed that the way I was feeling was common. And I shouldn't complain because you know it's not right to complain. You just need to get on with it. And also, culturally I'm Greek Cypriot I don't know if I can say that but I'm also the oldest daughter in London for my family. So, I care for my grandmother and I look after my parents, but I can't be sick. You know, I just have to get on with life and just keep my head down and, and, and do what I can to help my family. So that was me then but then I had Lemtrada and yes going through Lemtrada itself is difficult. It's difficult. It's quite an intense medication to take. But actually, once you're past the phase of recovery from having the treatment, I felt like I could fly. Like my fatigue was lifted I felt like I was reborn, but I was a completely new person, and this is what life should feel like (LAUGHTER). I'm you know, I don't really struggle, I wasn't struggling with fatigue as much as I was prior to having treatment. It was like I had a new lease of life basically. But I can't take that for granted because um there are times when I do struggle so if I haven't had a good night sleep. I know that I need to, you know the whole spoon thing. So, I need to know where to prioritize my energy and most of the time prioritizing my energy is getting to work and doing what I can, or you know more than what I can normally at work because my work is quite stressful. And then coming home, hopefully get into the gym and by the time I've done that, it's bedtime for me. I can't manage much more but I think touch wood but I'm pretty lucky if I compare myself to my counterparts who have MS. So, I really don't try to complain. I tried to keep this positive as I can.

Dipesh: You mentioned that you are the elder sister and you also look after your grandmother. So, how did being diagnosed with relapsing remitting multiple sclerosis impact those around you? And you're responsibilities to others?

Alexandra: Well, when I was first diagnosed my parents and my younger sister were with me and I told them. I'm one of seven children. So, I told them I don't want anybody else to know until I deal with this myself. I don't want to tell anyone. So, for a few months I didn't confide in the rest of my family. I just kept it within the four of us that were in the room at the time that I was diagnosed. I think because I was in a, in a, in a kind of a mindset of denial really you know, and I wasn't sure what I would tell people anyway because I didn't fully understand what was going through myself. So, for the first few months after I was diagnosed nothing changed, I kept on with my responsibilities and I kind of buried my mind in the sand as it was. Like I just carried on as if nothing had happened or at least other people around me couldn't notice that anything was really going on with me, but then in the evenings I was maybe either in my bedroom or wherever when I was on my own and then at that point, I was doing research and probably looking at things I shouldn't really have been looking at. You know, unhealthy images of MS. I was predominately looking at worst case scenarios and then upsetting myself even more. And then dealing with those emotions on my own and suppressing them. So, I kind of shut myself off from everyone else. But once I did tell my brothers and the rest of my family. Most people were very supportive. I think, they were all afraid of what Lemtrada was and what the risks were because I basically told them in preparation for me having treatment because things were then going to change in terms of me being able to continue to look after my grandmother whilst I was recovering and also being able to baby sit for my brothers because they all have children and I also babysit so, uhm I had to kind of say, I won't be able to be around the kids for a little while and these are the reasons why and I think they were concerned that this is a fairly new medication and maybe the risks with too great and that I should maybe see things out and see how the MS affects me before I do anything drastic. But for the most part people were very supportive, uhm I just had to be quite assertive about my choices and I had to be confident in the decision that I made in the research that I have done and be able to I guess reassure my family that actually my decision was the right one and I was comfortable with the risks that were involved. But yeah, for the most part, everyone was supportive.

Dipesh: You touched upon work as well…

Alexandra: Yeah.

Dipesh: How has relapse remitting multiple sclerosis impacted your work?

Alexandra: Well, how does my work impact on my MS (SHARED LAUGHTER). I think, whilst I was going through my diagnosis, I confided in my manager. I'd say fairly late, later on in the process I confided in my manager. Uhm, he is brilliant. You know, he's very supportive, he would allow me to take hospital appointments on the on-work's time. And let me go home early sometimes if I was feeling particularly low. Particularly because I think he could see that I haven't told any of my colleagues and kind of knew what I was going through and I'm the type of person that will make up the work anyway, so, uhm, I work, I don't know if, I, I don't know if I can say… well I'm a civil servant so as you can imagine high caseloads, high stress. We work well over the amount of hours that we are contracted to work so if there were days that I was off like I was able to go home early the following day I'd be working you know more than the eight- or nine-hour day anyway. I think work can on the one hand be useful because whilst I was struggling with the emotional impact of the diagnosis work, work was a necessary distraction. It was something to kind of take my mind off of things and also it gives me purpose, a sense of purpose. But also, on the other hand, where work is so mentally draining, I felt like I was going home, um already quite, already drained. Sorry to use the same word. I was already mentally drained but then I was you know basically screwing myself over again because I'd spend hours researching online so my brain had no time to relax no time to shut off. And I was just basically running myself into the ground with work and then my own personal research and I was exhausted like totally exhausted. Now since I've had the Lemtrada, so I've been quite lucky, my GP supported mean having twelve weeks off every time I've had infusions because of the nature of the work that I do, I go into prisons as well. So, I'm working with a population that are likely to have infections. So, where I have a low immune system, I've been signed off for the initial twelve weeks where your immune system is re populating. Although, it won't re populate to the full extent, your B-Cells will repopulate a little bit in the twelve weeks. And when I returned to work, I mean, it's been, it's been really good. Um, there are measures in place to protect me. They can't always guarantee that they'll work the way that they meant to. So, to give you an example, my caseload is supposed to be capped at 100%. But there are times where I've gone over that because it is a civil service and we're short staffed. But generally, I do feel that my manager is somebody that I can approach, and I can say to him that I'm struggling, and he will make adjustments for me. When there are times where I'm particularly feeling under stress, I notice that I will feel as if I’m vibrating. Uhm, I describe it to people as if I feel a bit giddy like, it's, it's like there are, now I can't even really explain it, but like all the nerves in my body are kind of excited if that makes sense and then I will feel the pins and needles in my left leg. So, I know that I'm under stress and the stress is causing physical, it’s manifesting physically. And when I am particularly tired, uhm, I will have some blurred vision in my in my right eye in particular. So, what I will do then is I will hopefully if I can stop working, take a break. But I can't lie to you, I think in the current job that I am in, I don't think it's something that's sustainable for somebody who has a condition that is impacted by stress. It's something that I've, I've managed to keep doing but for how long I really can't tell you. Because you can shrug off blurred vision or pins and needles in your leg but if my symptoms were to get worse. You can no longer ignore those you know. You have to, you have to at one point sit down and say to yourself right, “is this really worth me risking a deterioration in my health over a pay-check?” Which is not why I do the job. I do the job because I love the job and I love my clients but somebody else could do my job and hopefully that person will be better at it because they won't be compromised by something like MS.

Dipesh: So, when you ask yourself that question about your symptoms and the stress and is it worth having a pay-check, it seems as though you know that there's maybe someone else that could potentially do your job, but I guess you still go back? You mentioned that you're signed off work for a while, but you would go back to work?

Alexandra: I will, I will be going back to work. Although work don't know this but I'm actually in the process of, I’m looking for other jobs. But the trouble is, it's very hard to, I think for anyone who, I’ve trained specifically to do my job, so I've got a degree and I've also got a graduate diploma, so I'm qualified for the role that I do. And I'm unfortunately not qualified for much else. You know that's just the way society works these days, so if I wanted to have another graduate job at the same sort of pay, I'd have to retrain. I'd have to go back to university. So, I'm kind of in a bit of predicament about what I would do about work. I either accept a pay cut and work somewhere else. Hopefully somewhere low stress but then I'd have the added stress of maybe financial issues. So, it's, it's a catch twenty-two uhm. I would like to try to do my job or something in line with my job for as long as I can. And I think the solution bar me retraining and finding something completely different, the solution is me being a stronger advocate for myself and having better more defined boundaries and sticking to those boundaries and maybe, maybe I don't like to say this but starting grievances if managers don't comply with the safeguards are put in place to protect me at work. Because it's all well and good the excuse being but we're short staffed, we don't have anybody else to give the work too.

But actually, if you carry on giving me the work, I may go off sick and then you'll be down another member of staff. So, you need to hopefully put things in place to stop me from doing that and knowing that I have MS chances are I’m more likely to go off sick than the next person. So, let’s try and work together so that I can be, so I can work the best of my abilities and for as long as possible. But that's something that I've struggled to do because I've always been a bit of a yes person. I don't like letting my managers down. I don't let him work down, especially because I've been a civil servant for so long. It's that kind of mentality. You know you just buckle down and get on with things and so I feel guilty, sometimes say, I've got disability, I can't do this, or can't do this the way that I used to do it or the way you expect me to do it, but I need to stop being so afraid of sticking up for myself at work.

Dipesh: So, the next question was pertaining to your understanding of DMT's. You mentioned that you've done a lot of research…

Alexandra: Yes.

Dipesh: So, I wanted to know what you what you thought DMT were designed to do? How do you think they would benefit someone with MS? Also, you mentioned that you were adamant that you wanted Lemtrada and you had a consultant which was sympathetic towards that. So, I guess, I wanted to also know also perhaps why Lemtrada and not another DMT like Tecfidera, for example?

Alexandra: OK, so at the time, this was 2018 when I was looking at treatments for MS. My first line of thought was stem cell replacement therapy. Because I, I was, I was really catastrophizing at the time and I was thinking quite drastically but obviously that's not given under the NHS unless you’ve had Lemtrada and unless I was willing to do a fundraiser my parents couldn't afford to pay for me to have stem cell placement therapy unless they were to sell their house and again that would have been extreme measures for anyone to go through or go down when you just been diagnosed with MS and you don't even know what the course of, or what your disease, what course of your disease will take. So, I was looking at what was the next best and it was either Lemtrada, or Ocrevus. Because Ocrevus was just bought out in 2018 as far as I remember and because Ocrevus was fairly new, I looked at Lemtrada instead. But I think even if Ocrevus hadn't been new I would have been, I think I would have been pulled more towards Lemtrada because of the it's, it's a stronger drug in the sense that it causes permanent damage or a permanent change I should say to your immune system. Now the reason why wanted to go so hard hitting, and this might be controversial, I mean, you could, you could challenge me. I'm open to being challenged. But as far as I'm concerned, the other DMT's that are available on the market, do not really have a significant effect on the progression of MS. They may control relapses or so we believe. We believe that they might control relapses amounts but in terms of disability outcomes I couldn't see any other DMT having a significant impact on disability outcomes. So, what I mean by that is, somebody who doesn't take medication, what happens to them when they reach the age of 60 in comparison to somebody who does take a beta interferon and then when they when they reach 60 years old, both might still be using a walking stick. So, for me, I, if you do kind of a cost benefit analysis, the idea of having to inject myself once a week or twice a week and having flu like symptoms because of the injections for the next 20 or 30 years of my life and it not really meaning anything in the end was a waste of my time and energy. You know, that was how I feel about it. So, I looked at Lemtrada because it's something that will cause it definitely causes a permanent change that the clinical trials are quite promising at least for about 50% of people. And it's something that you, ideally you can do twice and then that’s you forever, hopefully. Uhm, you never have to think about having MS again. And I would hope that even though the clinical trials are I think only about 10 years on, there is data from trials done in the 90s, so people with MS at that time, there is still evidence of a change their immune system so the lasting impact of Lemtrada is something that I was particularly impressed. But I don't know if impressed is the right word because there are other lasting changes that Lemtrada can bring about you know negative side effects that aren't necessarily something that you want. But I was willing to take the risk. If you're going to take any medication, I think one take something that will definitely make a difference. Otherwise, there's no point. Yeah, that's it actually. Just, something that will make a difference or there's no point. So, for me, it was okay Lemtrada carries a lot of risks but it's the only one that can really make a difference other than Ocrevus so it's either that or nothing. And you face MS alone.

Dipesh: Did you say that you took Lemtrada in infusion form?

Alexandra: Yes.

Dipesh: And what was your experience of doing that?

Alexandra: So, in my first year. I only had, so it's five days of infusions and I had steroids for 3 days, the first three days. First, three days will be easiest because of the steroids that was given as well as antihistamines, you given antihistamines and steroids. Aside from having an infusion related rash at the time, uhm I felt pretty good. It wasn't until my fourth and fifth day where I had the maximum number of steroids that I was entitled to, uhm so I did my fourth and fifth day without any steroids. It was those days that I found I felt the roughest and by the fifth day, my, my heart rate had actually dropped quite low and I was in and out of consciousness I'd say, for the whole day. So, I was closely monitored on the fifth day because of that. Uhm, I struggled with the recovery for Lemtrada the first time around in particular. Uhm, I was basically, knocked off my feet. This time around, I only had three days of infusions, which is typical for Lemtrada. It’s always, after your first round, only ever three days that you do in the follow-up years. Its standard is two years, but if you need a third or fourth or fifth round, you can have. So, because it was only three days this year, I had steroids on either day. So, I felt really good actually. For the most part I felt quite good. My main difficulties were fatigue and some stomach upset so I had some stomach troubles. But generally, it wasn't as bad as my first round. The recovery has been difficult. As well, but again probably not as bad maybe because I knew what to expect so I was better prepared. Uhm, yeah.

Dipesh: When you say the recovery was difficult, would you be able to tell me what you mean?

Alexandra: OK, so in my first year, I'd say, the first week - I was in bed. I could barely get up. It felt as if I've been hit by a bus that your whole body is aching. You feel bone pain. But through understanding what takes place with Lemtrada, you know it's not something that, it’s not a decision you can make lightly. If this is a drug that you want, its intense. It eradicates your T and B cells so in order for your body to replace those it will do so from your bone marrow, so bone pain is actually fairly common or at least should be expected after you've had some kind of chemotherapy like this. Where, it's almost as if I could feel my bone marrow getting into work you know. (LAUGHTER) Even my spine like the insides of my bones hurt. That's how bad it was. So, I was bed bound for a little while and my lymph nodes was swollen on my neck but again, I'm guessing my lymphocytes were dying and whatever was happening in my body was happening, in the right place. Uhm, so I was fatigued for about for the twelve weeks, I'd say I was suffering with fatigue. So, what that meant for me was, uhm normal day, normal day to day activities were harder. I needed to take naps in order to get through a long day. I was very sensitive to heat. So, I would have hot flashes like somebody may be experiencing menopause might have. My skin would even feel hot to the touch. Uhm, I would experience UTI’s more so than the average person. Infections. Like I have diarrhoea often if I ate something that was maybe questionable. But for example, you have to be you have to follow a listeria diet, which you have to be very careful. Even fruits and vegetables. Make sure that they are thoroughly washed so if I went to somebody's house for dinner, I might eat something thinking it would be okay but actually it would give me an upset stomach so, uhm, you have to be much more careful about where you eat, where you go. Uhm, I couldn't really be around my brother’s children, because again children, they are a hub for bacteria and, uhm, I had to isolate myself a lot. At least keep myself kind of away from groups of people so not only you kind of experiencing all of these issues, but you're doing it on your own because you can't really mix, too much with too many equals. So, over the Christmas period, I guess it was quite hard for me. This time around, I've had similar symptoms uhm, but I think an added symptom that I never felt before was hoarseness in my voice. I found it; I had some difficulty breathing when I had my infusions this time around. And it kind of affected the sound of my voice for about a week or so. When I returned home but that's gone now, so. Hopefully it stays gone.

Dipesh: After you've had the infusions? Because you earlier on mentioned that the treatment made you feel like on top of the world, I was wondering if you can tell me a little bit more about how you feel after you've had the treatment?

Alexandra: OK. So, once I had my first round of Lemtrada, once I started to feel a little bit better, obviously, it's not going to be easy, I say this to people that are expecting to have the treatment. It's not easy at first, but once you start to recover, I felt like, Uhm, I've I started going to the gym, which is something that I couldn't really do before. I never did before, and I felt like I had a lot more energy. I was walking to work. Walking back from work, which is forty-five minutes there and forty-five minutes back and still going to the gym. So, I had bounds of energy. Uhm, I was at the Duracell rabbit. Now, I don't know, this could be my thyroid, I mean, I don't know it could be. I could have an overactive thyroid. Or I could have had an overactive thyroid at that time, but that's something that is being measured by the hospital that I am under.

But for me, I felt like I had a new lease of life where, uhm, I felt invincible in a way. And these are things other people take for granted being able to walk for two hours a day and still go to the gym and do a full day’s work and then not feeling like you're dead at the end of the day because when I'm coming home at the end of the day, I'm still making myself dinner. Or, watching something on TV and not falling asleep in the middle of whatever I am watching. Uhm, I was socializing more. So, I noticed that before having treatment, I'll make excuses not to go out on the weekends with my friends because I was just too tired to go. I couldn't be bothered, I'd say. But really, and truly it is because I was too tired. The thought of going out is what I couldn't be bothered about. Uhm, but yeah, I was making more effort to socialize. I had the energy to socialize. I had the mental capacity and the mental energy to actually socialize with people. So, I think for me Lemtrada has been a godsend. Uhm, but I don't take for granted that some people have had serious side effects of the drug and I'm not out of the woods, you know. I could potentially develop a serious side effect. So, it's something that I need to be mindful of. Uhm, but fingers crossed for me - I'll stay healthy.

Dipesh: You mentioned Lemtrada has had a really positive impact on yourself holistically, you mentioned earlier that you’ve made changes to your diet also. So, you incorporated a ketogenic diet, which is elevated in its fats and you've made amendments to your working patterns as well. So, I guess I'm wondering how would you be able to know if it was just the Lemtrada or other elements that helped?

Alexandra: Very difficult to say. So, I don't try to, uhm, not to pinpoint at any one thing. Uhm, I think all of them combined have made a difference. It's actually. It's a scary thought sometimes because I've, I've recently changed my diet again. So, there’s not enough research, I think on the impact of diet and MS. There is some. There's definitely some research. Uhm, but there's not enough. So, I find that a lot of people with their MS that I've spoken to, are reluctant to make dietary changes because where it's not it's not proven maybe they don't really want to muddy the waters or do anything that might actually turn out to be a hindrance themselves or irrelevant really in the long run. Whereas for me, it was something that I felt like was, just as important as the medication because I don't need a piece of paper or an article to tell me that eating organic and eating more fruits and vegetables and eating less processed foods is going to be better for my body. It's, I think, not only is the actual behaviour and the process of eating better food better for my body, but also the idea of being able to control some of the aspects of my health is also good for me mentally. So, it's kind of an allrounder in the sense that I felt better in myself physically. But also, better about my choices. I respect myself more. Uhm, I've proven to myself that I care about myself enough to make these changes. And I'm very disciplined. So, I've learned so much about myself in the past year and a half. Uhm, I'm actually proud of the person I've shown I can be and how I've stuck with these changes. Sorry I went on the big there.

Dipesh: No not at all. It is really interesting when you said that you have learned a lot about yourself. You touched upon earlier, you mentioned being a bit more boundaried with your time and your capabilities at work and also in your private life in terms of looking after your brother's children. But I guess, I'm wondering what else have you learnt about yourself?

Alexandra: I think that it’s a really good question. I think, before I was most certainly unhappy in my life before I realized I had a MS. And I was stuck in a rut in a sense, I was just literally going to work and coming home. And I guess expecting some kind of miracle moment where things will fall into place. I would meet a partner. We would get married. Have kids and live happily ever after you know. Whereas now, my perspective on life has changed that if you want something you have to go out and work for things. Stop taking life for granted. But that's easier said than done obviously. It’s knowing what do I actually want? And what type of partner do I want in light of my new diagnosis. You know, it has to be somebody who's open minded. Somebody who's caring, supportive. Who is going to be able to fathom all of my dietary restrictions and the amount of vitamins that I take every morning and the essential oils that have burning in the house and this is got to' be someone that I mean, this person might, not necessarily be realistic, but the point is I'm figuring out who I am, what I need, and actually taking the action to go out and get it. So, that means being more confident and I've always been somebody who can talk the talk but, actually, now, I've tried to put myself in situations where I'm not necessarily the most comfortable, but I'm forcing myself to make new connections with people. So, I will go to random seminars where I don't know anyone, but just to make friends and maybe learn something new. I've started a YouTube channel discussing my MS. I've made connections with people online. And I've started an Instagram page and everything. So, I think for me, I'm still learning who I am. But I think who I am is, someone, I'm proud of her, she's on a journey. She's not perfect. Uhm, but she's not so bad. Uhm, I have to stop being so negative sometimes. I'm a bit of too much of an inner critic and I'm learning to love myself more. This sounds all cheesy but it's very important I think because people with MS particular the people I've met online, uhm, they can be quite hard on themselves. Uhm, and they have a negative outlook on life, and I think that actually might have an impact on their physical impairments because when you've got a negative outlook, you're less likely to want to go out and get out. So, you're less likely to exercise and then when that happens and if it happens continuously then you're going to have more muscle atrophy and all of these things. So, you need to, there has to be an incentive for you to want to get out and that has to be I love myself. I want myself out there in the world, exposing myself to other people. I realize that I'm important in spite of having MS. Or maybe because I have MS. Uhm, yeah. Sorry (Laughter).

Dipesh: I'm really glad you shared that because it was part of the next question. I wanted to ask you which is more about your experience of not only MS and DMTs, but I guess one of the things I was wondering was, what has been the most challenging thing for you? Or a challenging part of the journey, so far?

Alexandra: Easy question. The uncertainty. Uhm. That and the not knowing and not being able to know, you know what, what's going to happen in thirty years. Uhm, so I know that there's been times where I've said to my consultant "am I going to be disabled in 25 years?" And he would look at me and say, "no of course not." But nobody can answer those questions for you. And where I'm somebody who as I said before, I like to know things. I'm, I'm quite controlling. I'd like to understand things and pick at things and analyse things. So, the idea of not knowing and struggling with that uncertainty has really taken its toll on my mind at some point and my mind will wonder and I'll start to imagine worst case scenarios. But the way that I've kind of, stented myself, I've got a mantra that I have developed that is tomorrow is an illusion. Uhm, I think for me in particular, uhm, and culturally as well, the, the ideal of life is you get married and you have children. And you raise those children and you be a good mother and then when those children have children, you'll be a good grandmother. And for me, I think about being a burden on my children or a burden on my grandchildren so, I have to, I have to bear in mind that nothing in life is ever promised. And that there are no guarantees anyway, so even if I didn't have MS, I could get into a serious car accident and that might disable me anyway. Uhm, or, I might have MS, but I'm hit by bus and I die. You know, I'm very mobile when I die, but I die anyway, so, nobody knows what the future will hold. You can have an idea or a fantasy about what that might entail but actually you need to live more in the moment, uhm, I think that's been the hardest thing for me to kind of understand, is take risks now and stop thinking so much about five years' time, ten years' time, and live for now.

Dipesh: Would you say that part of this way of thinking has been due to the benefits of taking DMTs? Or where would you attribute this way of thinking from?

Alexandra: Uhm, I can't lie. The fact that I've had Lemtrada has definitely given me a sense of security because I feel as if I have some armour on you know to protect me from relapses. Uhm, and I think if I was taking a less effective DMT. I don't think I feel that way. I only feel this way because I'm very sure of the benefits of Lemtrada. So, for sure before I had Lemtrada, remember if we go back, I was diagnosed in August. I didn't have Lemtrada until November. From August to November, I was almost driving myself insane with the fact, with the idea that I was unmedicated. And I was walking around, you know, maybe going to encounter my next, relapse and this one was going to be a big one. And I haven't given myself any medication, so how is that going to protect myself or prevent anything from happening? So, I think props go to people who are diagnosed with MS and they are comfortable going ahead without any medication and just taking life as it comes. They are so secure in mindset you know, but I'm not secure enough to do that. So, for me as I've said Lemtrada kind of it's like I'm wearing my armour and then all the other additional things that I do to hopefully protect myself long term.

Dipesh: And when you mention the additional things you mean like the diet and things like that?

Alexandra: Yes.

Dipesh: I don't know if you're aware, a couple of months ago, I think it was in November, the NICE guidelines published a paper talking about the effectiveness of taking CDB oil for spasticity in multiple sclerosis. So, I was wondering what your thoughts were about taking additional forms of treatment to enhance recovery and your journey with MS?

Alexandra: I would be open to it, I've looked at the impact of it. Part of my research... (participant receives a telephone call).

Alexandra: Sorry.

Dipesh: You were saying about CDB.

Alexandra: Yes, I'm so I looked into that as well. Uhm, I see the benefits. I, also, I don't do it regularly, but I have smoked cannabis when I've felt particularly, uhm, there was one moment that I recall it was between August and November 2018, when I was waiting for treatment and I hadn't told anyone at work what was going on yet and I was really under a lot of stress and I felt like my whole body was physically shaking from the vibrations. Internal vibrations. And a friend of mine smoke’s cannabis, so I rang her up and I asked her if I could go to her house. I took a little bit with me, brought it home. Rolled it. Smoked it. And the effect was almost immediate in terms of calming my nerves and I was pretty much symptom free for the moment I was under the influence of cannabis. For me personally, it's something that I can enjoy socially. Uhm, but I would struggle with it being something that I take on a daily basis. Maybe in the mornings because I don't know how I would function at work if it caused, if these are CDB oils without the THC element, then I can, I would be happy to take something like that on a daily basis because that wouldn't cause the, I don't know what to call it, the high effect. But then at the same time, I also have my own opinions. Based on research that I've read on the effectiveness of CDB oil without the THC element. So, I don't know if I would take the CDB unless I knew that without the THC it would still be having a positive impact on me because I think the THC also has a part to play in that I don't know if you know, but there is somebody, he's a celebrity called Montel Williams and he is a talk show host in America. He has MS. He's in his 60s and he still walking and talking is very mobile and he credits most of his good health to cannabis and this is when I first came across the whole cannabis and MS, uhm, relationship. And he's actually brought out his own cannabis products in America. So, I think in America it is something that they've been they've kind of known for a long time and people have been self-medicating with cannabis is fairly new over here in the UK. Well, it's not actually people don't medicate with cannabis officially in the UK, but you can go to Holland

and Barret and buy CDB. But it's not high-quality CDB. So, the types you'll get in America is going to be much better, but I've never used those so I, I can't say what they like.

Dipesh: Final question. What would you say to an individual with relapsing-remitting multiple-sclerosis who is about to commence DMT?

Alexandra: I would say, uhm, don't listen to your consultant. Uhm, in the sense that do your own research be your own advocate because if I hadn't had known what DMT I wanted and was sure of my choice, I don't know if it would have been offered to me as the first port of call. Maybe I would have been offered one of the ABC's, which is what I hear a lot of my MS counterparts are offered as first line therapies, which is all well and good. I see, I see the argument for being offered, uhm, like less dangerous DMT's. But, as I've told you before, I don't see the long-term benefits of taking those medications so for me, it's a waste of time. So, I would probably be a bit of a pessimist I'd say to somebody who's just been diagnosed. I would say look at the most more intensive drugs and consider those if you can't consider those side effects, I won't even bother looking at the other DMTs. But if you need to take another DMT, then I would do so in conjunction with lifestyle changes, including you know regular exercise, dietary changes, you know, I don't necessarily want to recommend that they become vegan because that's a personal choice of mine but cut out processed foods make sure your plates, you know are full of more vegetables and try and choose organic if you can. Take vitamin-D because that itself has been proven to have a significant effect on relapse rates so that is something that doesn't have a negative impact on the body. There are no serious side effects from taking vitamin D past 60,000 units per day so if you can take 10,000 units, 20,000 units do so. And other vitamins that you might need. Meditate or pray or whatever it is that you can set yourself daily. You know trying to reduce stress from your life and all of those elements combined should hopefully help you because I think, I don't want to, sorry, I know this isn't the purpose of your research, but I don't want to be the type of person advocates only DMT's. I think, medicine isn't going to help you if you can't rid yourself with the root cause of the problem and the root cause for a lot of people with MS could be bad lifestyle and stress, so you need to kind of help people in all parts of their life for positive outcomes.

Dipesh: Correct me if I'm wrong, but I guess, it sounds as though when you see the consultant, they see you as someone with MS and then they are saying “okay, let's give you a DMT which can solve the MS.” But what you are doing is going away looking at yourself holistically and thinking can I make changes to my diet, maybe pray more, maybe put oils on around the house, and then you're doing your research. But it seems that you're not perhaps getting that kind of advice or not having those discussions with your consultant. Would that be fair to say?

Alexandra: That is fair to say. My consultant, so I remember when my first consultant I had as my case was being transferred from my original hospital to my MS Hospital, he had told me that 10,000 units of vitamin-D a day was dangerous. And then I showed him the paper that said that it wasn't and there were some trainees in the room with him, some students at the time who were all nodding in agreement with me because they had also seen that paper. So, if I had trusted his word at that time, it would have been false information or it wouldn’t have been, I wouldn’t say false, because he obviously read a paper, at some point in his life, but I'm saying he didn't have the up-to-date relevant information. And then with my new consultant who I get on greatly with like his brilliant is very open minded. However, I think there is uhm, I think most consultants, this is an assumption of mine, I think most are reluctant to advise on diet because there isn't enough evidence, so they don't want to necessarily recommend something or put their name on something. So, most have recommended to me, that I have spoken to a Mediterranean diet. Now Mediterranean diet can mean a lot of things, it's very vague. But generally, when I've spoken to my consultant about my diet, he is very supportive. He doesn't dismiss the lifestyle changes that I've made and actually commends me at times to say, “you know, I can see that you're doing really well, you've lost weight, you look healthy, you know, you don't look like a patient of mine.” But, generally, consultants, I don't think are given the autonomy or the authority to advise on these issues. Uhm, which is a shame because MS Management isn't simply medication It's a number of things.

Dipesh: OK. Thank You for agreeing to take part in the interview, before we end is there anything else, you'd like to add, or anything that you may feel it's important?

Alexandra: Just quickly I just wanted to say that I think there's a lot of disparity across the UK in terms of like if I compare my experience in a very well established hospital in London to people that I've met online in, in hospitals outside of London, not everybody is offered the same type of treatment or the same service and I think that's quite disheartening because again I'm in a cohort people that's very fortunate surely because of my geography and where I live and so I think what, what might, what, what might be important is if you look at DMT rates across the UK and seeing, sorry and then seeing where the DMTs are taken up more frequently and maybe not so frequently and thinking about why that might be and is that because of the quality of care or maybe the lack of information? I mean, I don't know.

Dipesh: Ok. So maybe from your experience of speaking to other people with MS, there's like a disparity between the treatment people are getting perhaps in London, for example, to up North.

Alexandra: I know for certain that and the local hospital to where I live doesn't actually, it's not, set up to deliver Lemtrada. So, if you wanted to have Lemtrada, if you were a patient at the hospital, your case would need to be transferred to another hospital and to another consultant. So, some people are reluctant to change hospitals because they built up good relationships with their consultants and they don't want to leave. People don't like change. People don't like having to go into central London if they live on the outskirts of London. So, making services, maybe more uniform as well across hospitals. Yeah, that's my two pence (Laughter) I won’t say anymore.

Dipesh: Thank You. Anything else?

Alexandra: No Thank You.

Dipesh: Thank You.

Alexandra: Thank You.