

EXPLORING THE EXPERIENCES OF PERSONS WITH MULTIPLE SCLEROSIS
WHEN SELF-HYPNOSIS IS APPLIED

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ABSTRACT

Multiple Sclerosis (MS) is an unpredictable and generally debilitating disease for which there is no cure. Conventional treatments have significant side-effects and involve considerable risks. I conducted an interpretative phenomenological analysis with eight participants to identify the common themes in the experiences of persons living with MS, specifically: how this disease affects one's quality of life (QoL), what role pain plays in their lives, and what changes, if any, were experienced when the participants applied self-hypnosis. Most participants reported that their idea of QoL was fluid. All participants reported their QoL was shifted by MS, and some reported both positive and negative changes. Four main themes emerged in how these participants defined and measured their QoL: (a) connectivity with others, (b) level of functioning, (c) positivism and (d) hope. The unpredictability of the disease was addressed by all participants and reported by almost all to affect each of these four domains. Seven participants reported feeling daily physical pain and that pain had a profoundly negative and complex impact on their lives. Pain was found to be physically tormenting, mentally consuming, and emotionally inundating for these participants. The physical, mental and emotional constituents of pain can all have a drastic impact on one's existence, and the combination was reportedly devastating for some. After four weeks of self-hypnosis, the following changes were identified: (a) improved emotional regulation, (b) intrapersonal improvements (c) improved cognitive functioning, and (d) improved physiological state. No negative or adverse effects were reported by any of the seven participants who completed the study. Six participants reported positive changes in their journal entries. Six participants reported they were extremely likely to use hypnosis in the future and to recommend

hypnosis to others. With an increased understanding of the complex impact that MS has on people, we can learn to better support, treat, and empower those with MS. QoL is subjective, yet invaluable. Based upon this initial case study inquiry, it is possible that self-hypnosis could be an effective and personalized tool for meeting the multifaceted needs of this population.

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Dedication

To the incredible women and men who bravely shared their stories with me and live powerful and emotional experiences that test and strengthen them in profound and incalculable ways.

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Chapter 1

Multiple Sclerosis (MS) is a challenging and generally debilitating disease that affects millions of men, women, and children worldwide. This study explored three topics of investigation: (a) the experiences of persons with MS in order to better understand how this disease affects one's quality of life (QoL); (b) what role pain plays in their lives; and (c) what changes, if any, were experienced when the participants applied the therapeutic tool of self-hypnosis.

An estimated 350,000-400,000 people (roughly 10,000 of whom are children) in the United States have been diagnosed with MS, that equates to roughly one in 750 people, with approximately 200 new cases being diagnosed each week (Brill, 2008; Hill, 2003; Kalb, 2012; National Institute of Neurological Disorders & Stroke, 2010; National MS Society, 2011; Prosser, Kuntz, Bar-Or, & Weinstein, 2004). These numbers remain mere estimates as the Centers for Disease Control and Prevention in the U.S. do not require physicians to disclose new cases (National MS Society, 2011), thus the magnitude of this disease can only be conjectured. Currently, there is no cure for MS and conventional treatments have significant side-effects and involve considerable risks (Kalb, 2012; National Institute of Neurological Disorders & Stroke, 2010; National MS Society, 2011; Prosser, Kuntz, Bar-Or, & Weinstein, 2004). While scientists worldwide are searching for effective treatments and possible cures, the estimated over 2.5 million people in the world battling MS (Gist, 2004; Vanderbilt, 2004) are in urgent need of reprieve from their daily symptoms.

MS is a very individual disease; each person's experience with MS is distinct, no two cases are alike, and symptoms can vary daily for any given individual (Vanderbilt,

2004). Davis (2010), a medical doctor, remarked that “in some ways, each person with MS lives with a different illness” (p. 6). For this study I conducted an interpretative phenomenological analysis (IPA) of MS and hypnotherapy with the intent to delve more deeply into a few cases and gain a better understanding of what living with the diagnosis and disease of MS can look and feel like, and how applying the tool of self-hypnosis can affect individual experiences.

Rationale

As scientists and medical researchers continue to investigate the epidemiology, prognosis, treatment, and future cure for this disease, research designed to identify immediate treatments that may increase the quality of life for persons with MS is vital. This study is designed to introduce researchers, practitioners, those living with MS and those without, to the thematic adversities and experiences of persons living with this challenging disease. Through this study, I hope to bring focus to the lives affected by MS and to create a more human-focused launching point for future studies and the development of personalized treatments. An overarching objective of this study is to focus on the humans who live with this disease and explore the effects that this disease has on them and their quality of life. Because of the unique nature of this illness, it is imperative to pursue a better understanding of the perspectives and privations of persons living with this diagnosis in order to identify how to better help and support them. This study is designed to gather information and narratives from those living with MS in an effort to reveal more of what living with MS can look and feel like. With an increased understanding of the needs of this population, researchers, practitioners, general society,

and others who share this diagnosis can learn to better address the human needs beyond the course of the disease.

Furthermore, this study introduces the therapeutic tool of hypnotherapy and explores its potential influences on persons with MS. Where pharmacological treatments increase the longevity of lives in those with MS (MS National MS Society, 2012), these medications produce a variety of negative side effects that can adversely modify the quality and form of their daily existence (Durelli et al., 2002; Jelinek, 2005; MS National MS Society, 2012; Prosser, Kuntz, Bar-Or, & Weinstein, 2004; RxList, 2010a; RxList, 2010b; Stachowiak, 2009). In this study, the intervention of hypnosis was offered to the participants as an adjunct treatment for their at-home use. Research has demonstrated that hypnosis has been found beneficial when treating various conditions, both psychological and physiological (Gay, Philippot, & Luminet, 2002; Gholamrezaei, Ardestani, & Emami, 2006; Gonsalkorale, Houghton, & Whorwell, 2002; Elkins, Jensen, & Patterson, 2007; Elkins et al., 2004; Peynovska et al. 2005; Spiegel & Bloom, 1983).

This study explored how each of the eight participants applied and experienced the tool of hypnosis (e.g. the frequency, objectives, experiences, etc.) and what they found applied to their specific needs. This added intervention demonstrated how hypnosis can be implemented and utilized to support those with MS. The results indicated that self-hypnosis appears to be an effective and personalized tool for meeting the multifaceted needs of this population. The information gathered through this study will potentially benefit not only those who are suffering from MS, but also practitioners and the general scientific community seeking to better understand the various components of this multifaceted disease.

Topics of Investigation and Methods

This study explored three topics of investigation. First, this study was intended to unveil and delineate the experiences of eight participants with MS to better understand how this disease affects their quality of life. Second, this study introduced an intervention of hypnotherapy and all of the participants had an opportunity to engage with and apply the tool of self-hypnosis. And third, this study examined what role pain plays in the participants' lives and what changes, if any, are experienced when this population applies the therapeutic tool of self-hypnosis. Through interviews, journals, and surveys, I originally aimed to connect with and gather diverse material from five to eight adults with MS that reveal themes illustrating what living with MS can look and feel like and how that experience is affected by the application of self-hypnosis. This study began with eight participants and completed with seven. This study followed an interpretative phenomenological analysis model and assumed an individual relativistic worldview. At the completion of this study, my aim was to better understand how MS affects ones' quality of life, what role pain plays in the lives of my participants, and how one's experience with this disease can be influenced by applying the tool of self-hypnosis.

Summary

In this first chapter I introduced the rationale behind this bipartite study that aimed to unveil some of the experiences of persons who live with MS and discover how they incorporate and experience the tool of self-hypnosis. In Chapter One I underscored the three topics of investigation that this study was created to address and provided a

brief introduction to the method, worldview, and strategies of inquiry. In Chapter Two I will explore the literature on MS and hypnosis.

Chapter 2: Review of Literature

This study explored the experiences of persons with MS to better understand how this disease affects one's quality of life. Additionally, this study explored what role pain plays in their lives and what changes, if any, were experienced when the participants applied the therapeutic tool of self-hypnosis. This section contains a review of the literature on MS and hypnosis, including the epidemiology of MS and common treatments – both traditional and alternative. This is vital information as it offers a medical and logistical framework of how this disease is taking shape, affecting, and wreaking havoc in the bodies of these individuals. Hypnosis will also be introduced and defined as it was applied as an intervention in this study. The most common myths regarding hypnosis will also be expelled to better educate readers to what hypnosis is and is not. Finally, empirical findings will be introduced from studies involving hypnosis and clinical ailments (e.g. irritable bowel syndrome, fibromyalgia, etc.) as well as research that is focusing on hypnosis as analgesia.

Epidemiology of Multiple Sclerosis

MS is a chronic, often disabling, and unpredictable disease that attacks the central nervous system (CNS). MS is thought to be an autoimmune disease in which the body's own defense system attacks myelin, the fatty covering insulating nerve cell fibers in the brain and spinal cord, forming scar tissue (sclerosis); a process known as demyelination (Kalb, 2012; Milo & Panitch, 1999; National MS Society, n.d.c; Prosser, Kuntz, Bar-Or, & Weinstein, 2004). Myelin facilitates the smooth, high-speed transmission of electrochemical messages between the CNS and the rest of the body (Kalb, 2012; Milo & Panitch, 1999; National MS Society, n.d.c; Prosser, Kuntz, Bar-Or, & Weinstein, 2004).

When damaged, neurological transmission of messages may be slowed or entirely blocked, resulting in diminished or lost function (National Institute of Neurological Disorders and Stroke, 2010). Common symptoms of MS include fatigue, numbness and/or tingling, pain (e.g. trigeminal neuralgia, Lhermitte's sign, etc.), ataxia, dizziness, spasticity, visual impairment, and cognitive impairment. A survey from the University of Texas revealed that 48 percent of MS patients reported experiencing chronic pain (as cited in Hill, 2003, p. 33).

Genetic and environmental factors are thought to influence the natural course of MS, but to what extent and how is still under investigation (Abramovitz, 2010; Stüve et al., 2008). Diagnosis remains complicated as there is still no test (barring a microscopic examination of a CNS lesion) or imaging procedure (e.g. computed tomography [CT] scan or magnetic resonance imaging [MRI]) that can produce a unequivocal, standalone diagnosis; instead, diagnosis is often a rule-out process that applies the compilation of one's personal and familial medical history, record of symptoms, and neurological signs (Kalb, 2012; National MS Society, n.d.a). Because MS is a complex disease to diagnose, misdiagnoses and missed diagnoses are not uncommon (Hill, 2003; National MS Society, n.d.a).

MS is a capricious and degenerative illness, yet researchers have identified five differentiated disease courses that help ascertain the disease severity and response to treatment: Relapse-Remitting (RR), Primary-Progressive (PP), Secondary-Progressive (SP), Progressive-Relapsing (PR), and Benign MS, each with an unpredictable pattern of transition amid them (Davis, 2010; Gist, 2006; Hill, 2003; Kalb, 2012). Approximately 70-85 percent of persons have RR MS at the time of diagnosis, while only 15 percent

have a progressive type (Hill, 2003; Kalb, 2012). Studies that observed the natural course of MS have revealed that void of any disease-modifying treatment over half of those diagnosed with RR will develop a progressive type within 10 years, and 90 percent within 25 years (Hill, 2003; Kalb, 2012). Only 6-10 percent of persons with MS have PR MS, suffering from continual symptoms without remitting. The progress, severity, and specific symptoms of MS vary from one person to another depending on the course of the disease and the specific area(s) affected. Despite these variables, most persons with MS will eventually be affected by a significant degree of impairment, disability, and handicap (Mil & Poanitch, 1999). Furthermore, Hill (2003) cautioned that the term *relapse-remitting* is somewhat misleading, as very few persons with MS are ever symptom free and in total remission.

The prognosis of MS is variable, ranging from mild to very serious, depending on which nerves are attacked. The average life expectancy reported was found to vary but most sources agreed that persons with MS had only a slightly reduced life expectancy than those without MS (Compston et al., 2006); however, a rare type of acute MS can be fatal within weeks (W.D., 2010). Damage to the CNS typically occurs intermittently, therefore commonly allowing persons with MS to lead fairly normal lives (W.D., 2010); however, as the disease progresses the individual's symptoms increase in frequency, duration, and severity, resulting in impairment to their overall quality of life.

Traditional Treatments

To date, there is no cure for MS and no approved treatment for primary-progressive MS (Kalb, 2012; MS National MS Society, 2012). Currently, the FDA approved and licensed disease-modifying drugs (DMD) (also known as disease-

modifying therapies (DMT) and disease-modifying agents (DMA)) used to treat relapsing forms of MS (including RR, SP, and PR) are: Avonex® (interferon-beta 1a); Betaseron® (interferon beta-1b); Copaxone® (glatiramer acetate); Extavia® (interferon beta-1b); Gilenya™ (fingolimod); Novantrone® (mitoxantrone); Rebif® (interferon beta-1a); Tecfidera™ (dimethyl fumarate, formerly known as BG-12); and Tysabri® (natalizumab) (Kalb, 2012; Lim & Constantinescu, 2010; National MS Society, 2012; National MS Society, n.d.b). When taken long-term, DMDs reduce the frequency and severity of relapses and exacerbations – the worsening and/or appearance of a new MS symptom, decrease the accrual of lesions, and decelerate the disease (Durelli et al., 2002; MS National MS Society, 2012). Treatment via one of these DMD options is critical for slowing the natural progression of this disease; however all of these treatment options have significant side-effects and involve considerable risks (Durelli et al., 2002; MS National MS Society, 2012). Potential side-effects of these DMDs include, but are not limited to: flu-like symptoms, infection-site reactions, depression, suicidal ideations/attempts, anxiety, seizures, bowel and/or bladder problems, liver abnormalities/damage, myalgia, headache, nausea, jaundice, leukopenia, hair loss, heart problems, low red or white blood cell count, and potential harm to a fetus and potential miscarriage (Jelinek, 2005; MS National MS Society, 2012; Prosser, Kuntz, Bar-Or, & Weinstein, 2004; RxList, 2010a; RxList, 2010b; Stachowiak, 2009). Jelinek (2005) cautioned that (at the time of publication), none of the interferon studies had yet reported the side-effects of the long-term use of interferon.

Alternative Treatments

In addition to conventional treatment, complementary and alternative medicines (CAM) are commonly sought to manage disease symptoms due to the ineffectiveness of conventional treatment, anecdotal reports of CAM's benefit, and referral by physicians (Kalb, 2012; Olsen, 2009). CAM therapies include exercise, herbal and mineral supplements, psychological counseling, Reiki, acupuncture, hydrotherapy, cannabis, massage, and more (Gist, 2006; Kalb, 2012; Kruzel, n.d.; Olsen, 2009; Shinto et al., 2004). Naturopaths using CAM therapies for MS treatment report effectiveness on the outcomes of quality of life, symptom severity, incidence of relapse, and disease progression (Shinto et al., 2004).

Hypnosis

There are mixed professional opinions as to what hypnosis is, and if it in fact is even authentic in nature (Olson, 1984). The most prominent theory maintains that therapeutic effects of hypnotherapy are obtained through "the activation and employment of the ability to distort memory or perception" (Van Dyck & Hoogduin, 1990, p. 398). Hypnosis transpires when a participant is induced into a relaxed, suggestible state and then presented with post-hypnotic suggestions. This relaxed state is similar to meditation, quieting the judgmental and logical conscious mind, and allowing for deeper work to take place within the subconscious realm of the brain. The subconscious mind is literal and never analytical; it controls our involuntary bodily functions, emotions, impulses, creativity, and more (Olson, 1984). Although the hypnotized individual never loses consciousness and remains aware, a hypnotic state allows for increased accessibility to the subconscious without the interference of the overactive judgmental, rationalization,

and denial of the conscious mind, therefore increasing the individual's susceptibility to reconditioning and effectual change (Olson, 1984). Hypnotherapy combines the process of hypnosis with a healing treatment intervention, often seeking to alter a behavior or sensation. Olson (1984) described hypnosis as an altered state of consciousness with the following seven characteristics: (a) physical and mental relaxation; (b) increased fixed-focus of concentration; (c) ability to modify perception of sensory input (occurs primarily in deeper levels of hypnosis); (d) ability to modify memory; (e) ability to control normally uncontrollable physiological responses (e.g. blood pressure/flow and heart rate); (f) trance logic (increased toleration for logical inconsistencies; applied to altering self-defeating ideas, etc.); and (g) increased ability to accept and integrate suggestions.

Myths about hypnosis. Despite the renewed hype, hypnosis, under various names, has been employed for centuries. Lioffi, Santarcangelo, and Jensen (2009) maintain that suggestive therapy is possibly the oldest of all therapeutic methodologies. The acceptability and application of hypnosis has been scrutinized and periodically criticized by the medical and scientific communities, as well as various segments of the church (Hilgard & Hilgard, 1994; Lioffi et al., 2009; Olson, 1984). Since World War II, hypnosis has been gaining credibility as a viable clinical treatment (Olson, 1984). In 1948, dentists began applying hypnosis as a method for pain control (Amen, 2009). The Catholic church approved its use as a standard medical treatment in 1954 and it was approved by the American Medical Association and American Psychiatric Association as a legitimate therapeutic intervention in 1958 (Amen, 2009; Olson, 1984). A National Institute of Health Technology Assessment Panel Report has since acknowledged hypnosis as a viable and effectual intervention for alleviating pain for persons suffering

from cancer and other chronic pain conditions (De Benedittis, 2003). Despite these respectable gains, fallacies plague this method, misguiding both clients and professionals alike.

The most common myth surrounding hypnosis is that the participant will be under the control of the facilitator and can be forced to act against his/her will (Gfeller & Gorassini, 2010; Olson, 1984; Yapko, 2012). Another common misconception is that the client will be asleep and/or unconscious in a hypnotic state and will not know what is happening (Barabasz & Barabasz, 2008; Olson, 1984; Yapko, 2012), leading to a concern that he/she run the risk of not being able to wake and return to reality (Olson, 1984; Yapko, 2012). Others fear that they will become “stuck” in a hypnotic state. Yapko (2012) maintained that it is impossible to become stuck in hypnosis as it is merely a state of focused attention, and just as no other form of concentration has ever held someone captive against their will – neither will hypnosis. Some fear that hypnosis opens them up to evil, making them more susceptible to the devil or evil entities. It is another myth that only the weak-minded and gullible can be affected by hypnosis (Yapko, 2012). Many fear that they are unable to be hypnotized and understand it to be a passive activity that is done to them, versus an active process where they are inevitably hypnotizing themselves each time (Yapko, 2012). Yapko (2012) asserted, “the hypnotic process is an interaction based on mutual power, shared to attain some desirable therapeutic outcome...even the most responsive clients can refuse to follow the suggestions of a clinician if they so choose,” (p. 37). Many of these myths are provoked and sustained by stage hypnotists that, just as with all entertainers, are there to produce a captivating show, and not to be confined by fact and fidelity (Yapko, 2012). After all, a magician does not finish his

show by explaining how he tricked the audience with fallacies amiably titled “illusions.” Therefore, it becomes critical that in a therapeutic setting, the therapist reeducates the client about the differences between stage-hypnosis for the purpose of entertainment and clinical hypnosis (hypnotherapy) for the purpose of healing and dispels these common misconceptions.

Hypnosis and clinical outcomes. Research indicates that hypnotherapy has revealed beneficial client outcomes (Cowen, Saltmarsh, & Hayek, 2008). Hypnotherapy has been found to be a highly effective treatment for persons with irritable bowel syndrome (IBS), addressing and decreasing the symptoms of extracolonic symptoms (e.g. abdominal pain, bloating, bowel habit disturbance), as well as psychological factors of depression, anxiety, and increasing overall quality of life, with improvements lasting 2-5 years (Gholamrezaei, Ardestani, & Emami, 2006; Gonsalkorale, Houghton, & Whorwell, 2002). Hypnosis has been found to significantly decrease pain, anxiety, depression, and reduce the increase of pain over time (as disease progressed) in cancer patients (Elkins, Jensen, & Patterson, 2007; Elkins et al., 2004; Peynovska et al. 2005; Spiegel & Bloom, 1983). Dignes et al. (1997) explored the use of self-hypnosis on children and adults with sickle cell disease, and found that those who participated in self-hypnosis intervention reported a significant reduction in pain days. In the treatment of osteoarthritis pain, hypnosis treatment has led to substantial and significant decrease in pain intensity (Elkins et al., 2007; Gay, Philippot, & Luminet, 2002). Gay et al. (2002) found in their experiment, however, that during follow-up, the differences between pain reduction in the hypnosis group and relaxation group were not statistically different. A study by Haanen et al. (1991) revealed that persons with fibromyalgia found significantly better outcomes

on measures of muscle pain, fatigue, sleep disturbance, distress, and patient overall assessment of outcome, even after a three-month follow-up, when compared to physical therapy (as cited in Elkins et al., 2007).

Some clinical outcome studies maintain that the effect of hypnotherapy is related to hypnotizability in certain disorders such as pain and anxiety, but not in the treatment of addiction or habit disorders (e.g. smoking cessation) (Van Dyck & Hoogduin, 1990). Other research argues that high hypnotic susceptibility is not a precondition for the successful application of hypnosis in patients with chronic pain (Carli, Huber, & Santarcangelo, 2008). Patterson and Jensen (2003) studied fibromyalgia patients and argued that the relationship between hypnotizability and the efficacy of analgesic hypnosis is weaker in patients than in healthy persons undergoing nociceptive stimulation and ruled out relaxation as a cause for analgesia (Carli, Huber, & Santarcangelo, 2008; Patterson & Jensen, 2003).

To the suggestion that placebo analgesia is more effective in patients than in healthy persons undergoing painful stimulation, Carli et al. (2008) suggested the possibility that chronic pain itself modifies a person's response to treatment via hypnosis, resulting in changes in pain coping strategies and potentially increasing the individual's probability of having a placebo response (Carli, Huber, & Santarcangelo, 2008). Van Dyck and Hoogduin (1990) argue it improbable that results of hypnosis are due to placebo effect, as placebo reactivity appears to be variable as a positive reaction to a placebo and does not foretell the future reactions of that individual. Furthermore, they argue that hypnotizability has been documented as a relatively stable trait variable, while placebo reactivity appears to be state variable, making it seemingly improbable that the

same processes are operating in both hypnosis and placebo reactivity (Van Dyck & Hoogduin, 1990). Carli, Huber, and Santarcangelo (2008) acknowledge that although hypnotic and placebo analgesia maintain common cortical activation patterns, the two processes may denote the effect of different cognitive strategies.

Hypnosis and pain. Research indicates that hypnosis leads to reduction in experienced pain and is proven to have a longer treatment effect than other interventions (e.g. medication management, physical therapy, education, biofeedback, autogenic, relaxation training, etc.) (Carli, Huber, & Santarcangelo, 2008). Elkins, Jensen, and Patterson (2007) reviewed 13 controlled prospective trials on hypnosis in the treatment of (non-headache) chronic pain problems (e.g. arthritis pain, cancer, sickle cell disease, low-back pain, temporomandibular pain, and disability-related pain) and found that hypnosis interventions consistently produced significant reduction in pain associated with a variety of chronic-pain problems and was regularly found to be more effectual than non-hypnotic interventions (e.g. physical therapy, education, etc.) for certain types of pain. These studies, however, reportedly had a number of design weaknesses (e.g. low sample size, insufficient long-term follow-up, lacking credible controls for placebo, etc.) thus additional research needs to be done in this area (Elkins, Jensen, & Patterson, 2007). It is still not fully understood how each component of the hypnotic treatment (e.g. suggestibility, expectancy, relaxation, hypnotizability, etc.) contributes and influences the analgesic effect of hypnosis; some research emphasizes the impact of expectancy on hypnosis, while others discount it (Carli, Huber, & Santarcangelo, 2008).

Although evidence supporting the efficacy of hypnosis in the down-modulation of both acute and chronic pain is mounting, the neural mechanisms underlying hypnotic

states, responses to hypnotic suggestions of analgesia, and the cognitive and psychological processes involved, remain largely unknown (De Benedittis, 2003). Through the use of electrophysiological and neuroimaging (De Benedittis, 2003), researchers are slowly gaining scientific understanding of this seemingly mythical occurrence.

Amen (2009) reported that a hypnotic trance changes peoples' brain functioning and can be observed under neural imaging to have an increase in left hemispherical activity. Neural assessments revealed an increase in alertness and heightened attention exhibited as cognitive and neuronal activation (Amen, 2009; Fingelkurts, Fingelkurts, Kallio, & Revonsuo, 2007). Fingelkurts et al. (2007) found that hypnosis produced reorganization in the composition of brain oscillations, particularly in prefrontal and right occipital EEG channels, with spectral patterns that were wholly dissimilar from those observed during non-hypnosis.

Hypnotic suggestions of analgesia educe congruent changes in the activity of the pain neuromatrix, the modulation of the spinal nociceptive response, and in the vascular correlates of acute pain (Carli, Huber, & Santarcangelo, 2008). The hypnotic suggestion of analgesia is speculated to alter pain processing on multiple levels and locations within the CNS, the peripheral (motor, sensory, and autonomic structures), spinal, and supraspinal cortical levels (activity occurring above the spine) (De Benedittis, 2003; Hilgard & Hilgard, 1994). At a peripheral level, hypnosis is thought to modulate nociceptive input by down-regulating A delta (sensory) and C (unmyelinated) fibers stimulation and reducing sympathetic arousal (De Benedittis, 2003). On a spinal level,

hypnotic analgesia has been determined to be linearly related to a reduction of the nociceptive flexion (RIII) reflex, a polysynaptic spinal reflex (De Benedittis, 2003).

Lioffi et al. (2009) reported that in conditions of acute/procedural pain, treatment of hypnosis, in contrast to no-treatment or “non-hypnotic” interventions, resulted in significantly decreased pain at least 50 percent of the time, and functioned as well as the control conditions in the remaining 50 percent of the trials. Equally, when hypnotic suggestion of analgesia for acute/procedural pain was compared to other “viable” treatments (e.g. relaxation training and Cognitive Behavioral Therapy), hypnosis scored superior to these treatment modalities in approximately half the trials with no alternate treatment exceeding the efficacy of hypnosis (Lioffi et al., 2009). Lioffi et al. (2009) argue that hypnotic approaches to analgesia of acute/procedural pain is often more effective than other treatments, and rarely, if ever, less effectual; and the established reliability of hypnosis as an effective treatment for pain reduction supports the use of hypnosis as an appropriate “first line” psychological intervention for pain management for many pain conditions.

Lioffi, Santarcangelo, and Jensen (2009) report that hypnotic suggestions for analgesia can influence pain at “its generation at the periphery, secondary sensory neurons sensitization, and modulation of endocrine/immune responses through the modulation of autonomic activity” (p. 1). They further suggested that the experience of pain, the elicitation by certain sensors projecting into the CNS through afferent pathways, is germane for homeostasis and denotes a particular emotion associated with a homeostatic behavioral drive (Lioffi, Santarcangelo, & Jensen, 2009). Furthermore, in functional chronic pain syndromes, specific alterations transpire in the autonomic,

endocrine and somatic motor systems interactions, consequently resulting in dysregulation involving peripheral, spinal and brain mechanisms (Lioffi, Santarcangelo, & Jensen, 2009).

Lioffi, Santarcangelo, and Jensen (2009) reported that psychologically interceded forms of pain reduction, as with hypnotic suggestion of analgesia, both modulate nociceptive reflexes and pain-related autonomic activity elicited by peripheral stimulation as well as the supraspinal pain-control system. Functional imaging tests have documented activation in the midcingulate cortex, area 24'A as directly facilitating the vicissitudes in pain perception linked to hypnotic suggestion, as hypnosis was found to improve functional modulation between midcingulate area 24'A and an array of cognitive, sensory affective, and motor-related neural regions, resulting in changes that literally reduce pain perception, not just one's response to pain (Lioffi, Santarcangelo, & Jensen, 2009).

Olson (1984) stated that, "Hypnosis is perhaps our most powerful clinical intervention short of medication, however it is also the intervention most sensitive to the client's ultimate purposes...if for some conscious or subconscious reason the client resists, hypnosis will have little or no effect" (p 414). Persons who are highly hypnotizable are speculated to possess greater cognitive flexibility and stronger attentional filtering abilities than persons who have a low level of hypnotizability (De Benedittis, 2003).

Based upon the previous findings and controversies, this study intends to explore how this therapeutic tool of hypnotherapy can be applied and experienced by persons with MS. Hypnosis can be a powerful tool that offers individuals sanction over their own

treatment and management of symptoms, yet there is much to be discovered about the best practice of hypnosis as analgesia for chronic pain. The particulars of frequency, mode (recording versus live session), standardized versus individualized scripts, and best practice for training persons in self-hypnosis, have yet to be determined (Elkins, Jensen, & Patterson, 2007). Elkins, Jensen, and Patterson (2007) found that some persons report experiencing an immediate reduction in the severity of pain following hypnosis while others experience a decrease in pain after repeated practice of hypnosis and asserted that persons who engage in self-hypnosis more frequently “benefit more and may have more long-lasting gains” (p. 284). I am interested in discovering how the persons in this study apply and experience this tool as it relates to their individual drives, needs, curiosities, beliefs, biases, fears, and more.

Summary

This chapter contains a review of literature on MS and hypnosis. It introduced the current theories behind the epidemiology of MS and common treatments – both traditional and alternative. Because hypnosis is the intervention applied in this study, it was defined and explained, as well as its common myths dispelled. Finally, empirical findings from studies involving hypnosis and clinical ailments (e.g. irritable bowel syndrome, fibromyalgia, etc.) as well as research that is focusing on hypnosis and analgesia were introduced. The following chapter will expand on the specific methods of this study.

Chapter 3: Research Design and Methodology

This study explored the experiences of persons with MS in order to better understand how this disease affects one's quality of life. Additionally, this study explored what role pain plays in the lives of those affected and what changes, if any, were experienced when the participants applied the therapeutic tool of self-hypnosis. This chapter covers the methodology of the study. The philosophical worldview with which this study was approached is further expounded and the purpose overview and the three topics of investigation are detailed. This chapter also includes information about the population and sample that was studied and the research design and methodology that were applied. The specifics on the data collection process and procedures and data analysis are expanded upon as well. Next, this chapter explains how this study addresses the essential principles of credibility, validity and reliability. Finally, this chapter addresses how human participants were protected in this study.

Philosophical Worldview

This study was explored through the philosophical worldview of individual relativism. Individual relativism maintains the perspective that each person's *truth* is relative to the distinctive virtues and experiences of that individual as shaped by their exposure, culture, language, values, education, personality, genetics, etc., and rejects the notion that there is a *reality* apart from one's perception of it. The term *relativism* is suggestive of a relationship – that something is connected to, arising from, and/or determined by its relationship to something else (O'Grady, 2002). Garcia-Carpintero (2008) asserted that propositions are appraised relative to possible worlds and that a proposition may be evaluated as true relative to one world and false relative to another.

For example, the proposition that Van Gogh was a talented artist is true relative to some standards of taste, and false relative to others; the proposition that Sally is short is true relative to some standards of height, and false relative to others. Diagnosis, prognosis, identity, perception, pain, personal exploration, meditation, relaxation, empowerment – where each of these words may instantly trigger ideas, narratives, beliefs and emotions, those projected meanings are very individual. There is no normative or truth but individual experiences that are to be recognized and respected as real and profound, it was therefore anticipated that each individual would not only have their own definition of quality of life but also their own explanation of how MS plays into their lives. I created this study to explore each participant's individual, subjective interpretation of their interactive experience with MS and the practice of self-hypnosis with the aim to find shared themes.

Purpose Overview

The purpose of this study is twofold. First, this study is designed to better introduce researchers, practitioners, those living with MS and those without, to the thematic adversities and experiences of persons living with this challenging disease. Through this study, I hope to bring focus to the lives affected by MS and to create a more human-focused launching point for future studies and personalized treatments. Too often we get absorbed in the epidemiology and medical treatments of diseases, especially those that threaten the lifespan of its victims. Where we are fortunate to live in an age where disease modifying treatments exist and promote the longevity of the lives of those with MS – this disease and these treatments gravely modify the quality and form of their daily existence. This study is designed to gather information and narratives from the experts –

those who experience MS firsthand daily – in hopes to reveal more of what living with MS can look and feel like. With an increased understanding of the needs and privations of this population, researchers, practitioners, general society, and others who share this diagnosis, can learn to better address the specific needs of the humans with this disease.

The second function of this study was to explore how self-hypnosis can affect persons with MS. Research to find adaptable, innocuous, and easily accessible treatments to help persons with MS is vital. Self-hypnosis was offered to the participants as an additional tool for them to use as they see fit. This study then explored how each of the participants applied and experienced this tool (e.g. the frequency, objectives, experiences, etc.). The purpose of this intervention was to learn more about how self-hypnosis can be implemented and utilized to support this population. Research demonstrates that hypnosis has been found beneficial when treating various conditions, both psychological and physiological. This study was designed to explore what persons with MS find applicable to their specific needs. Where it was unclear as to whether or not the application of self-hypnosis would be of any help, it was my personal aim to explore alternative options to assist this special population.

Topics of Investigation

This study explored three topics of investigation: (a) the experiences of persons with MS in order to better understand how this disease affects one's quality of life; (b) what role pain plays in their lives; and (c) what changes, if any, were experienced when the participants applied the therapeutic tool of self-hypnosis. This exploration started with the investigation of what role MS plays in the lives of my participants and how living with this illness looks and feels from their perspectives. The study was designed to

explore the participants' individual stories and then find emerging themes that propose larger, connected struggles and/or experiences. Once hypnotherapy was introduced to these individuals, the exploration of how these individuals applied and interacted with the therapeutic tool of self-hypnosis was investigated with the intention of seeing if emerging implications and patterns exist.

Population and Sample

This study applied purposive homogeneous sampling, seeking to include adults in the Greater Seattle area who had been formally diagnosed as having MS. Although both male and female participants of varying races were desired, MS is twice as prevalent in females as in males, and Caucasians are more than twice as likely as other races to develop this disease (National Institute of Neurological Disorders & Stroke, 2010). Therefore, a greater number of Caucasian female participants was anticipated. Also, due to the much higher prevalence of the relapse-remitting (RR) form of MS, it was anticipated that the majority of participants would have RR type.

Participants were solicited through multiple avenues. Recruiting of participants was conducted via posting the research opportunity online through the National MS Society website, Craigslist, and a private website. Additionally, in-person advertising was conducted at the Bainbridge Island and Seattle MS Walks on April 13 and 14th of 2013.

Compensation for participation included gratis treatment for all participants. All participants were provided self-hypnosis training and administration materials at no charge. All participants were also compensated with a small gift package containing gift certificates and other small mementos (worth around \$100 each).

Research Design and Methodology

I conducted an interpretative phenomenological analysis of MS and self-hypnosis. Willig (2008), explained that “phenomenology is interested in the world as it is experienced by human beings within particular contexts and at particular times, rather than in abstract statements about the nature of the world in general” (pg. 52). I was interested in exploring how human beings perceive and experience life that is affected by the disease MS and the therapeutic tool of self-hypnosis. In phenomenology, the meaning attributed to perception is not an intellectualized reflection, but an intentional constitutive element of experience itself (Fischer, 2006; Willig, 2008). Thus, a phenomenological perspective contends that multiple individuals inherently perceive and experience a shared environment in profoundly different ways (Willig, 2008). This study explored the experience of MS and hypnosis through the personal meanings that persons intuitively attribute to it.

Interpretative phenomenological analysis is a branch of phenomenological analysis that works from the premise that direct access to the participants’ worlds and experiences is impossible for a researcher to access (Willig, 2008). The analysis produced by a researcher is not only once removed from the veritable experience, but also under the influence of the researcher’s own view of the world and the interaction between the researcher and participant (Camic, Rhodes, Yardley, 2003; Willig, 2008). Interpretative phenomenological analysis was selected as the strategy of inquiry for this study as I recognize that although I am actively engaging with this population, I am an outsider as I do not have MS. I explored and produced an interpretation of these individuals’ explained experiences, an interpretation of their interpretations. Where I

strove to capture the authentic and accurate quality and texture of these imparted impressions, I recognize that I cannot produce an unadulterated rendition of such as I do not have access to its primary source. Through direct interaction with each of my participants, I gained insight into their individual impressions, experiences, and attributed meanings to this disease and therapeutic tool.

The study outline includes the following and will be further delineated below. I individually interviewed all eight adult participants at the onset of the study. Once all participants had been interviewed, all participants were invited to attend an orientation to hypnosis meeting. At this orientation, the participants completed all forms and received their participation materials (e.g. journals, CDs, etc.). All participants then had a full four weeks to listen to their hypnosis CDs and complete their journal entries. At the end of the four week period participants met once more to complete a final survey, submit their journal entries and collect their compensation gifts.

Data Collection Process and Procedures

To gather the data that addresses my topics of investigation, I used three sources of evidence: semi-structured interviews, journals, and surveys. Each of these sources allowed me to explore the participants' individual stories and experiences. These three sources of evidence are explained in further detail here.

Semi-structured interviews. All participants were interviewed one time, prior to the introduction of hypnosis in a one-on-one recorded session. Although I had reserved the right to conduct an additional interview with select participants at the closing of the four week study, I opted not to due to high quantity and quality of the data already collected. The locations for the interviews were at the Northwest University graduate

campus in Kirkland and at New Motion Physical Therapy on Bainbridge Island. The initial interview format was semi-structured, in that it followed the same interview guide (see appendix A) with divergence from the format if a participant shared something that required clarification or further explanation. The questions were used to prompt and drive the interview session, however each question was open-ended and intended to inspire the participants to open up, share their narrative, and divulge whatever came to their mind (Willig, 2008). The interview included a combination of descriptive questions (e.g. How did you come to learn that you have MS?); structural questions (e.g. How do you define and measure quality of life?), and evaluative questions (e.g. What does it mean to you to have MS?). Minimal notes were taken during the interviews as to monitor the non-verbal communication of the participants and to support and maintain rapport-building between the participants and myself. All interviews were audio recorded and transcribed.

Orientation session. After each of the participants had completed their initial interview, all participants were invited to attend an orientation meeting at Northwest University in Kirkland or at New Motion Physical Therapy on Bainbridge Island to educate and train them on the use of self-hypnosis and to further acquaint them with the study protocol. To commence this meeting, all participants signed a confidentiality and consent form (see Appendix B) and completed a demographics questionnaire (see Appendix C). I then presented the participants with a PowerPoint™ presentation that educated them on hypnosis (e.g. explanation of the process, common responses, expel myths, etc.), gave instructions regarding the journals, and closed the presentation with a question and answer session. Participants were provided with suggested application for

hypnosis (e.g. repetitive usage, suggested settings, etc.) and given a brief overview of some of the scientific data that supports and rebuffs its efficacy. I believe that this information was imperative to offer participants prior to their application of the intervention so that they were informed and educated consumers. The participants were then given six pre-recorded hypnotherapy scripts in CD format for their take-home use. The frequency, setting, and order in which they applied these scripts were at the sole discretion of each participant. All participants were asked to document their application and reflections in the provided journals. In addition, instructions for the journals were given during these meetings. The orientation at Northwest University was videotaped and a copy provided for those who were unable to attend either session prior to receiving their hypnosis material.

Journals. All participants were given a journal with four entry pages and a self-hypnosis log (see Appendix D). It was requested that the participants fill out the date and script number of every application of hypnosis in their “self-hypnosis log”. Willig’s (2008) work was the inspiration and guide for how these journals were applied in this study. All participants were asked to complete four journal entries, one weekly, for the duration of the four week intervention portion of the study. This study required only four journal entries as Willig (2008) cautioned that keeping a pain journal can increase the amount of pain that some participants experience. While these journals focus on topics beyond pain, each entry does contain a body diagram where the participants were asked to mark areas that they have experienced pain in the last week and two Likert scales to numerically rate their pain at its worst and least on a 10-point scale within that same time period. Additionally, each entry also contains three open-ended prompting questions and

a miscellaneous section where they were able to add any additional impressions. Willig (2008) proposed that collecting the participants' impressions privately and throughout this process, versus in public settings (e.g. one-on-one interview) and solely in retrospect may reveal more detailed accounts of the participants' experiences. The participants submitted their journals at the final meeting. For those who were unable to attend this meeting, their journals were collected and their final survey and compensation package were delivered using alternate arrangements.

Surveys. At the final meeting, all participants were asked to complete a final survey. This survey is comprised of both fill-in-the-blank and Likert scale questions (see Appendix E). The purpose of this survey was to obtain some final reflections from the participants. As previously stated, for those participants who were unable to attend the final meeting, alternate arrangements were made to issue them their final survey, collect their journals, and give them their compensation package.

Data Analysis Process and Procedures

After collecting the data from the interviews, journals, and surveys, I analyzed the material with the intent to find emerging themes that point at larger, connected struggles and/or experiences of how MS affects one's quality of life, the role pain plays in these participants' lives, and what changes, if any, they experienced when self-hypnosis was applied.

Semi-structured interviews. Before the data could be analyzed, the oral data collected from the interviews had to be transcribed into written form. The recorded interviews were professionally transcribed verbatim, however the emphasis of the transcription remained on the linguistic features of the dialogue. Where long pauses and

non-words (e.g. “hmmm...” or “ummm...”) were omitted, things like laughter, false starts or repetition of words were included. The content of the responses was the primary focus. Once transcribed, the scripts were formally analyzed, as outlined below.

Journals and surveys. Where the data from the journals and surveys originate in written form, both contain open-ended and Likert scale questions. The open-ended questions were analyzed in the same manner as the interview transcripts. The Likert scale responses from both of these sources of evidence were entered into table-format that allowed for within-case and cross-sectional analysis. This format highlighted patterns of consistency and changes within participants’ scoring, and revealed similar patterns shared by two or more of the participants.

Analysis of data. Interpretative phenomenological analysis assumes an idiographic approach, first assiduously analyzing the individual cases prior to integrating them with the remaining data (Willig, 2008). The analysis of the individual cases, including the interview transcripts and open-ended journal and survey questions, took place in a multipart movement as outlined by Willig (2008). The first step in this analytical process involved me reading the texts multiple times and jotting down unfocussed notes (e.g. thoughts, observations, questions, associations, etc.). The second step involved rereading the texts and identifying and labeling themes that I found characterized each section. The third step involved clustering themes identified in step two and adding organization to the analysis. Finally, a fourth step was applied to the most data-rich case. This step entailed creating a cluster chart that summarizes the structured themes of this case and highlights those themes that best represent the quality of the participant’s experiences.

Once all of the individual transcripts had been analyzed with steps one through three, I integrated the data by cross referencing each of the subsequent cases against the summary chart of the first case (the case for which step four was applied). The themes of the initial case were used to evaluate and code the other cases, and any additional emergent themes from the succeeding cases were added to the chart and reexamined against the first case.

A second coder also reviewed the raw data and recorded general themes for each case. I then used those themes to cross reference my findings for each individual case from my primary analysis. All themes that pertained to the three topics of investigation aligned with my original findings. This procedure created a progressive integrated list of themes until a list of master themes had emerged. These themes were then used to explain the larger, connected experiences that exist in the impact that MS has on one's quality of life, the role that pain plays in their lives, and the changes, if any, that were experienced when they applied self-hypnosis.

Reliability, Credibility and Validity

This study assumes the philosophical worldview of individual relativism, maintaining the position that each person's truth is relative to the distinctive virtues and experiences of that individual and rejects the notion that there is a reality apart from one's perception of it. Additionally, the literature maintains that MS is a unique disease that affects every person differently. Therefore the focus of this study was not on producing strict, replicable results, but more so on maintaining a credible and reliable research model that is conducted in an accurate, transparent, and systematic manner so that the study can be replicated.

Whereas the interviews and surveys were conducted in public spaces, each participant underwent self-hypnosis and wrote their corresponding journal entries in the comfort of their own environments (e.g. homes, offices, etc.) to increase the ecological validity of the study. To increase the reliability and ethical measures of the applied intervention, all six of the hypnosis scripts were constructed and composed by clinical hypnotherapist, Tracy Adams of Cornerstone Hypnotherapy, LLC and then reviewed by Barbara Dailey, DNP, ARNP, CCMSHt, FIB, for the sole use and purpose of this study. (All other citing and resources for these scripts are available upon request). Finally, the integrity of the analysis was increased with the methodical application of multi-level coding and cross-sectional comparison.

Protection of Human Subjects

The procedures of the Northwest University Human Subjects Review Board were followed. Due to their medical needs, these participants may be considered a vulnerable population. All participants were encouraged to maintain their medical regimen under their medical care provider during the duration of the study. Although research does not suggest it necessary to recommend participants seek medical consent prior to participating in this study, I recommended each participant to do so at their own discretion prior to their enrollment. All participants were informed in writing of the researcher's scope of education and experience as well as notified of any limitations to confidentiality. The consent form also outlined the criterion for participation and informed participants of their right to withdraw from the study at any time and for any reason (see APPENDIX B). All participants were assigned a numerical identification code that was used in lieu of any personally identifying data (e.g. names) to protect the

confidentiality of all participants. Those numerical codes will be used to reference to their information throughout this paper. All written documents were, and will be, maintained according to current HIPAA laws.

Clinical outcomes exhibit that hypnosis has been found to be a positive intervention for pain patients. Lioffi, Santarcangelo, and Jensen (2009) asserted that there are no potential risks of treatment by hypnosis; “it is safe and does not produce adverse effects or drug interactions” (p. 2). Hypnosis can provide a safe, effective, and enjoyable experience for persons with little-to-no adverse side-effects or reduction of normal function and/or mental capacity (Lioffi, Santarcangelo, & Jensen, 2009). Yapko (2012) argued that hypnosis is not harmful, but instead it is the ineffective and/or inappropriate use of the tool that can cause harm. Yapko (2012) explained, “Ineffective use of any skill, whether it be surgery, psychological testing, or giving haircuts, can hurt someone,” (p. 39). To ensure that the participants of this study were provided with appropriate and effective uses of hypnosis, all participants were trained in advance and provided with professionally created scripts. Because the term “risk” is subjective, the following potential concerns were addressed with all participants. It may be difficult for some to allow themselves to recognize and feel their pain, an important part of a holistic mind-body exercise. Some persons experience mild dizziness after leaving a hypnotic state, but this usually passes quickly. All participants were reminded to take their time and not get up too quickly. Also, some feel very emotional before, during and/or after treatment; this is an important aspect of treatment and I encouraged participants to recognize this as a natural release of emotions and recommend they not be concerned.

Unlike many traditional treatments for pain management, there is no threat for the development of tolerance to the hypnotic effect and it is an easy-to-learn skill that provides a personal sense of mastery and control over an individual's tribulations and helps to counter the feelings of helplessness and powerlessness common to chronic pain sufferers (Lioffi, Santarcangelo, & Jensen, 2009). Additionally, hypnosis is not a restricted treatment, but can be generalized to the various conditions that hinder an individual (e.g. management of nausea and vomiting, insomnia, anxiety, etc.) (Lioffi, Santarcangelo, & Jensen, 2009). Given the supportive research, I was confident that the participants in this study would not suffer adverse reactions to this intervention.

Summary

This chapter outlined the methodology of this study. The philosophical worldview from which this study was approached was expounded upon and the purpose overview and the three topics of investigation were further detailed. This chapter also included information about the population and sample that was studied and the research design and methodology that was applied in doing so. The specifics on the data collection process and procedures and data analysis were expanded upon as well. This chapter clarified how this study addressed the principles of credibility, validity and reliability. Finally, this chapter addressed how the participants were protected in this study.

Chapter 4: Data with Analysis

In this chapter I present my findings and analysis of the data. This chapter begins with the demographic information of the participants that made up this study and reviews the methodology. Contextual findings are then presented to provide the reader with some background data. This study explored the experiences of persons with MS in order to better understand how this disease affects one's quality of life. Additionally, this study explored what role pain plays in their lives and what changes, if any, were experienced when the participants applied the therapeutic tool of self-hypnosis. These three main topics of investigation are addressed in this chapter and the master themes that emerged from my interpretative phenomenological analysis of my participants' shared experiences are revealed.

Demographic Information

Participants were recruited at the MS Walks of Bainbridge Island and Seattle, through social networking (e.g. Facebook) and through word of mouth. The first eight men and women who demonstrated interest in the study and met the criteria were admitted. All eight participants completed the demographics questionnaire, semi-structured interview, and orientation process, and received their journals and CDs. Seven of the eight participants completed the study and submitted their journal and final survey.

The ages of the participants ranged from 30 to 62 with a mean of 48.5. Five of the participants were female and three were male. Seven identified themselves as Caucasian and one as Caucasian/Korean. Because MS is twice as prevalent in females as in males and Caucasians are more than twice as likely as other races to develop this disease (National Institute of Neurological Disorders & Stroke, 2010), these ratios were

anticipated. Six of the participants were diagnosed with the disease course of Relapse-Remitting (RR); the remaining two were identified to have the form Secondary-Progressive (SP). It was also projected that due to the much higher prevalence of the RR form of MS, the majority of participants would have RR type. The participants were first identified to have MS as recently as one year and as long as 32 years ago with a mean of 12.4 years. It is important to note, however, that the time of diagnosis does not necessarily coincide with the onset of the illness. Also, there is a relationship between the amount of time the participants had been affected by MS and the severity of their symptoms. Those who had been affected longer reported a more severe impact on their lives. The group of participants was heterogeneous: two participants had been diagnosed one year ago, the others 3, 4, 7, 25, 26, and 32 years ago. Three participants reported gait issues; two of the three are dependent on supportive devices for mobility (e.g. wheelchair, walkers, canes, etc.), and a third reported using a supportive device in her home only. Seven participants reported taking the DMDs: Tysabri[®] (4), Tecfidera[®] (2) and Copaxone[®] (1); the eighth participant recently discontinued all DMDs.

Worldview and Methodology

This study was explored through the philosophical worldview of individual relativism, thus holding the position that each participants' *truth* is relative to the distinctive virtues and experiences of that person, and that there is not a *reality* apart from one's perception of it. Because there is no normative or truth in individual relativism, but only individual experiences that are to be accepted as real, I had accurately anticipated that each individual would not only have their own definition of quality of life but also their own explanation of how MS has affected their lives. An interpretative

phenomenological analysis was conducted to further explore how these participants perceive and experience (a) a life that is affected by MS and (b) the therapeutic tool of self-hypnosis, and to seek a further understanding of their attributed meaning to those different experiences through the exploration of their shared individual stories. Because phenomenological perspective contends that multiple persons inherently perceive and experience a shared environment in profoundly diverse ways (Willig, 2008), and the disease of MS is known to be a unique disease that affects every individual differently (Davis, 2010; Vanderbilt, 2004), it was no surprise that the eight participants presented eight highly individual stories of their journeys, emotions, victories, and struggles in their life with MS. No two participants discovered their disease in a similar way, or experienced daily symptoms that resembled another's. Where phenomenological analysis assumes that as an outsider to this population it is impossible for me to truly gain direct access to the veritable experiences of having MS, I would argue that even if I were a member of this group, personally facing the diagnosis and daily symptoms of MS, I would still be at the mercy of this degree of separation as each person's story, coping, pain, needs, and triumphs vary considerably. So where I humbly agree with Willig (2008) in that direct access to the participants' worlds and experiences are impossible for a researcher to access, I would respectfully argue that MS is a disease that may never be fully understood by another – even if those persons share the diagnosis, they are unlikely to share the same experiences. The differences seemed far stronger than their similarities at first glance; though through further exploration it seemed there are numerous strong themes that tie this population together.

I explored and produced an interpretation of these persons' shared experiences and strove to capture the authentic and accurate quality and texture of the imparted impressions while seeking common threads that would weave these unique stories together. Through my interaction with each participant and my data collection, I believe that I have gained insight into their individual impressions and experiences. As described in chapter three, I used the multipart analysis as outlined by Willig (2008). My analysis resulted in the detection of emergent themes.

Multidimensional Inquiry

Cassidy, Reynolds, Naylor, and De Souza (2011) asserted that "one aim of qualitative health research is to provide a multidimensional understanding of a person's experience of a health condition that goes beyond an everyday or common sense awareness and that leads to a more informed, nuanced, and empathic practice" (p. 263). MS is a disease that affects more than just the physical body. In order to achieve a more multidimensional understanding of my participants' experiences with MS, in addition to addressing the three main topics of investigation, the semi-structured interview was used to explore the various ways in which MS affected the participants' existence, including: how the participants discovered that they have MS, what it means to the participants to have MS, how that meaning has changed over time, what impact it has had on their families, etc. This additional information will not be detailed in this paper, but an overview is provided to help set the stage for the reader as to better help better elucidate the context of the three topics of investigation.

Contextual Findings

MS was reported as greatly impacting the daily lives of each of the eight participants, whether in the form of treating the illness with DMDs and other often invasive medication, dealing with various symptoms that range from numbness to excruciating pain, fighting unrelenting fatigue, and the changes to the participants' self-image and the manner in which others view and treat them.

When asked what it means to them to have MS, all eight participants reported that this meaning has grossly changed over time. Where most participants asserted that the implications of having MS has improved into a much more manageable issue, others (three of the eight) reported that having MS was taking a more heavy, disheartening, and negatively overwhelming turn for the worse on them and their families. It appears that the meaning one attributes to having MS is transient and has fluid implications. Where six out of eight participants reported having the initial response of "Why me?" and feeling tremendously frightened and overwhelmed, one participant reported feeling relieved at the diagnosis:

It was a relief because I had developed symptoms that couldn't be explained so having an explanation for this weird range of symptoms...so initially it was a big relief to know that there was a label that I could give to it, a name that I could give to all those things that have been happening. (208, personal communication, September 19, 2013)

Half of the participants reported feeling a sense of acceptance of- and coming to terms with- the disease. Those who are not facing debilitating daily symptoms to remind

them of the impact of their disease even reported that it may take another relapse to make MS real to them again. One recently diagnosed participant shared:

The next thing you know you're just back into your own thing. It's almost like that will change if I have another relapse or if something significant happens...because it's like you have the onset of, "Okay, you have MS." Then you freak out. Then you level out and you deal with it. Then because you don't really see anything changing around you, it's like out of sight, out of mind. Then you're just back into your old work stresses, relationship stresses, miscellaneous things that you're struggling with ... Other things start to take precedence. The MS part of it just goes in your back pocket. Absolutely I think that it will just be like anything else in life when that starts to trump everything else, suddenly that becomes the spotlight. Then the next thing you know it's a whole big thing again. It is something I'm nervous about, but it's a natural thing for my mind to just go – "well, you can't do anything about it. You're just going to have to deal with it when it happens." If nothing's happening now, just be thankful of that. (207, personal communication, August 19, 2013)

Others reported having a much different experience as they reportedly long for moments in which they can ignore their illness and just live and enjoy a "normal" life.

Over the course of their experiences with MS, all eight participants reported that the meaning they attribute to having MS has greatly shifted; some reported this as an improvement, while others shared that this has become drastically worse. All eight participants disclosed that the meaning of MS can – and often does – change daily.

Three participants reported that their diagnosis has been “a blessing in disguise” as it has led them to value and approach daily life in a way that they feel is a vast improvement from their former approach. One participant shared:

Now I see [MS] as a blessing in a certain sense, because I’m so much more aware of my body, how I react to other people, how I react in general. I’m much healthier than I was three years ago [when first diagnosed]. It’s weird to say that...but I’ve got a better mindset. I’m in a better place, so it’s a better feeling now than it was three years ago. (204, personal communication, August 2, 2013)

Another participant communicated:

What does it mean to have MS? It means that I pay attention to things that I wouldn’t have probably paid attention to before. In some ways it’s been a gift; it’s been an opportunity to live life in a different way than I probably would have been living it. I think it brought on a new level of self-care that I hadn’t had before and I changed my diet and paid more attention to what I can do physically and the limitations that are there just by virtue of the disease and its process. I think it enabled me to find what it meant for me to live being more authentic, to accept things, forgive in a way that I hadn’t done before. (205, personal communication, August 7, 2013)

The three participants who reported the positive changes that MS has inspired them to make in their lives also acknowledged that when their symptoms are intense and interfere with their daily functioning, the mental/emotional element of having MS greatly shifts. One of these three participants explained:

In thinking about the MS it has strengthened me, because it was like, “you know what, this is not how I’m supposed to be. I’m not supposed to be this angry and stressed out all the time”...It strengthened me to take a good look at my life and decide what was important...It was the MS that allowed me to re-architect my life ...On the other hand it means that sometimes my seven year old son is bringing me icepacks in bed and checking on me instead of me being up and about and playing with him. It depends on my mood sometimes. If I have a lot of symptoms and I’ve had to halt everything to take care of myself, I can engage in a little self-pity about the MS and be like “oh, MS sucks!” so there are both of those things; so it changes. My perspective on it changes from day to day. (208, personal communication, September 19, 2013)

Participants whose MS has had a more drastic impact on their daily functioning attributed this negative impact to their mental/emotional state in their provided responses. For instance, one participant who had been diagnosed with MS for twenty-six years explained:

Somebody has to push me in a wheelchair and I’ve lost all independence, and I’m horrified. I’m just truly at the end of my rope with it...I feel a total loss of who I was, what I was, and I just feel like I’ve lost everything! So it’s been horrific! (203, personal communication, August 2, 2013)

Another long term MS patient shared her mental/emotional struggle with MS because she felt consistently unable to function due to her MS. “It’s very frustrating and very overwhelming. I get very depressed at times. Not depressed, but just angry. You

know? I feel sorry for my family...I feel like I'm not being a part of the family at times. I feel helpless" (206, personal communication, August 7, 2013).

Seven of the eight participants shared stories where they would beg and plead with their bodies, as if their bodies were a separate entity. In many of their stories the participants anthropomorphized the MS, reporting instances where they would desperately plead with their disease. Helplessness and vulnerability at the hands of a disease that comes without any predictability appeared to be an overarching theme in the shared struggles of persons with MS. One participant explained:

When I was initially talking to the neurologist [after diagnosis], it affects – to be frank – from your eyes to your asshole. It's every part of your body that your nerves touch, it can affect. There's no way of predicting when, if, where, what, anything! That was my first thought, "Shit, okay. Well, am I going to have some sort of problem where I'm not going to be able to control my bladder or am I going to go blind or am I just not going to be able to walk?" (207, personal communication, August 19, 2013)

Another participant disclosed:

MS doesn't give me answers necessarily. The doctors, they'll help you and they tell you what you kind of expect but there's no standard like, "this will happen, this will happen, and this, and this, and this." There's no timeline and everyone I've talked to, it's different – like they never have the same exact thing, and I don't like that. I would like it if somebody just said, "You're going to feel like this and then it's going to be this way and then it's going to stop or it's not going to stop."

I'm just going, "Hmmm, I don't know, the wind might blow it that way today," it's annoying. (202, personal communication, August 2, 2013)

In addition to the anxieties around the uncertainties of the course of their disease, seven out of eight participants spoke at length about the exhaustion and frustration with having to plan around their illness, if at all possible. To illustrate the unpredictability of both the pain and the fatigue and the resulting necessity to ration and plan, one participant referenced "the spoon theory," a model created by Christine Miserandino in an effort to explain to her close friend what living with an illness or disability, in her case Lupus, feels like (Miserandino, 2010). This participant imparted:

There's so many things I want to do and there's so little time, but that time does seem shortened by the MS, because in May and June for six weeks I was pretty much in bed. I just couldn't, I don't know if you've heard the spoon theory? The spoon theory is this thing this woman with Lupus wrote that is you have this many spoons and that's all your energy to do stuff during the day, and some days with illnesses such as MS or Lupus, you wake up with half those spoons, and it costs a spoon to take a shower, and it costs a spoon to get something to eat, and so by the time you're ready to leave the house, you have two spoons left and a full day in front of you. That's what I had for most of May and June and it's like not only am I 44 but now, it's like I don't know which days I get to work with. (208, personal communication, September 19, 2013)

Miserandino (2010) explained:

The difference in being sick and being healthy is having to make choices or to consciously think about things when the rest of the world doesn't have to. The

healthy have the luxury of a life without choices, a gift most people take for granted (para. 6).

Another participant spoke similarly to this need to plan and strategize how to divvy her energy/ resources and weigh the “cost” of daily activities:

I’m not as strong as I used to be. I have to work harder to maintain a level, whatever that level is, and it fluctuates. Having to deal with being fatigued and the limitations of having to conserve energy and look at strategizing. What am I going to do today and what else do I need to be doing and what are my priorities? If I go ahead and push today, what does that make tomorrow look like in terms of my needing to be more calm and having a lower key day? Or do I do those back-to-back, realizing at some point that the bottom falls out?...I think it’s a different level for me of being conscious about the price I pay to keep pushing and living like I used to live. As opposed to recognizing that there’s still things that I want to do and I can, but I need to do them in a different way if that makes sense. (205, personal communication, August 7, 2013)

Both quotes clearly exemplify how like in Miserandino’s (2010) spoon theory, persons with MS also start their days without the luxury of unlimited possibilities and ample energy, instead having to painstakingly prioritize as the effects of one’s actions will be weighty.

Where half of the participants testified that MS has had little-to-no impact on their self-identity, stating that MS does not define them and was only a portion of who they are, the remaining four participants each shared how MS has indeed altered their self-identity and changed – sometimes drastically – who they had been and who they believed

they had become. Two reported a complete loss of identity, reporting that they had become entirely different people due to the MS. One participant disclosed:

Absolutely, 100%. If somebody said to me, who was [I] ten years ago? That was a different person. I am not even a tenth of what I was...I'm just not at all who I was, even though I am still inside, because of the limitations. I find I hold back from being that person...I'm not who I was; I lost that years ago. I was a pretty cool person, and I just don't feel like I'm ... the MS has just robbed me of that. I don't even feel like trying anymore to be who I was. (203, personal communication, August 2, 2013)

Five participants shared that they felt that MS compromised their ability to be the parent/grandparent/friend/professional that they used to and longed to be. Four used the term *robbed* when they referenced how they felt MS had prematurely taken away their right to fulfill these roles. Having MS requires an adaptation, not only to incorporate medical treatments and attend to symptoms, but also to restructure one's measurement of productivity, contribution, and self-worth. Six participants shared that they struggled to feel as if they were an active part of their families and communities. One participant explained how she had to constantly reframe what her identity was as her contributions and productivity had reduced greatly:

I can't be the person I was before, MS doesn't allow it...[MS] is a part of who I am and it has drastically changed who I am because I've always been such a "go, go, go, I can do a million things at once," and now I can't. The hardest transition for MS for me was that the idea, which is still entirely true, that I'm happiest when I'm really busy. The fact that I can't be busy like I used to be means I'm

trying to figure out how to be happy when that's what my personal identity was all wrapped up in, the "I can go and do anything times ten." Yes it definitely has changed my identity. (208, personal communication, September 19, 2013)

The question of whether they believe that MS has affected how others perceive their identity unveiled some intrapersonal and interpersonal struggles for all participants. Unanimously, all participants expressed the desire to be seen for who they are as an individual and not be characterized by their disease. Four of the participants asserted that they had made a conscious declaration early in their diagnosis that MS does not and will not ever define them. Many of the participants described the struggle between wanting others to see them as they did before the diagnosis and separate from the diagnosis, and yet expressed a frustration of others not being sympathetic to- and maintaining realistic expectations of- someone with MS. Participants whose pains and disabilities were not visible to others expressed a frustration that they felt people dismissed them and didn't "get it" because they didn't "look the part", didn't "look sick." One participant shared how she felt judged by others because she appeared healthy from the outside and spoke to how the public's ignorance often caused her to avoid sharing:

I find it kind of annoying because people look at you and they're like, "Oh, you don't look sick, you look good." I just stop talking about it to people because I hated hearing that... You can't look at somebody and tell how they feel. (202, personal communication, August 2, 2013)

Five participants shared how they believed that even their closest friends weren't able to conceptualize their illness because their friends never saw them when their MS badly flared and they were bedridden and/or looking ill. One participant recognized that her

friend stills sees her the same way that she has always seen her, “because she doesn’t get to see me when I’m lying in bed for six weeks,” (208, personal communication, September 19, 2013).

Those whose disabilities had become visible to others appeared to have answers that reflected the emotional torments of feeling like a spectacle, feeling judged by others, feeling as though they are treated as more disabled than they truly are, feeling minimized and belittled by others, and feeling pitied. One woman shared of her emotional struggle and shame as she not only felt bombarded by the negative attention, but also feared embarrassing her family and partner:

A hundred percent, they absolutely do [view me differently]. With a walker, it’s the look of pity. It’s the look of, “what’s wrong? She’s young. Did she have a stroke? What’s going on?” If we go to the mall and [someone is] pushing me in the wheelchair, it’s just, [sympathetic] “oh...” If we go to the store, the saleslady’s just, “oh, can I ...” it’s a sympathy thing...It’s just, it’s terrible. ...It’s sad; and at the airports, just getting to the gate, and everybody’s going [sympathetic] “oh...” and you have to load first; “oh, that poor thing.” It’s just ... it used to be really embarrassing, and it took a lot of time for me to use the walker in public...The next step was the wheelchair in public, and that was horrific! (203, personal communication, August 2, 2013)

Where six out of eight reported that their partners and families were highly supportive of them and their illness, that support was reportedly complicated at times. One complication was that four out of those six participants reported experiencing some guilt for burdening their partners and/or children. Three reported that the help and

support their families sometimes offered were not in-line with what their needs were, but actually felt insulting and minimizing. One participant shared:

My parents are just like, “Oh what can I do?” My mom was bringing meals over like I couldn’t cook or something. I’m like, “I still know how to cook. My brain didn’t fall out; it’s still there. I’m functional.” Then she was just doing whatever because she didn’t know what else to do. (202, personal communication, August 2, 2013)

Another participant explained how his children’s desire to help him often left him feeling frustrated, stifled and underestimated:

If I can get up the stairs, you know – and I can walk up the stairs as long as I've got a hand rail on this hand – I can do it and go up myself, I'll do it. When I can't do it, I'll ask for help but if I can still do it, so let me do it! You know, that's just the way I feel about it. Some people, it's like, "Dad, we're here to help you. Why don't you let us?" Because I want to do it! I can do it! I want to do it! When it gets to the point that I can't do it, I'll ask you for the help. They don't understand that probably. You know, it's a mental thing for me; if I can do it, I want to do it, you know? Don't make me more of an invalid. Just because I can't walk straight or walk right, don't think that you've got to do it for me. You know, they've got a hard time understanding that part sometimes. Then they'll look at me like “damn, he's so stubborn.” No, I'm not stubborn, it's just I can do it, so let me do it. (201, personal communication, August 2, 2013)

And where some reported sharing openly of their illness, many opted to share on a need-to-know basis due to the public's response to this illness. One participant articulated it well when she said:

I'm not very forthcoming with the fact that I have MS; the people who know are the people that need to know because they provide support. I don't generally go into a crowd of people and announce that I have MS. I am sensitive to the fact that people are judgmental and critical and have a story about MS. I choose not to tell a lot of people unless I feel a connection with them and that it's something that I want them to know. Unlike other people who walk and you can tell by the way they walk that they have a disability, people can assume or they'll say that they have it. For me it's something that I don't share with a lot of people. (205, personal communication, August 7, 2013)

This is but one of the reasons that MS tends to be a private illness. Five participants reported that they have avoided attending any MS support groups as to avoid seeing other people with this unpredictable disease. Where half of the participants reported feeling isolated with their illness, it appeared thematic that seeing the potential course that the illness may take was too daunting of a risk that far outweighed any potential support and encouragement that these groups may offer. One participant shared of his experience in attending a support group meeting after he was first diagnosed:

I went to one of those [support group meetings]. A lady in a wheelchair, nice lady about 40-ish or so, was there. First meeting I went to, she looked at me and we talked a little bit and she said, "Well what are you doing here?" I told her, I said, "Well I'm newly diagnosed and I just come here ... they suggested I go to the

support groups to learn a little bit." She says, "You know what? You're here, you're able bodied, I don't see anything wrong with you. You're walking just fine." She said, "Look around here. You're the one that's going to be putting away the chairs, cleaning up after everybody, helping out. You're going to see a few of us over here in our wheelchairs, crippled over, can't get along. You want to look at all of us? You want your family to see us and see what you might become down the road? You might, you might not be that." She says, "Why do you want to put yourself through this? Get the hell out of here and go live your life the best you can. When you really need it, come back. Right now, you don't need to be here. Get the hell out of here." I left with that, and I thought about that, and I said, "You know, that was probably the best advice I ever had." I never went back to a support group meeting again...I didn't need it. She told me the best thing I ever heard. I've lived with that, and it's been great. (201, personal communication, August 2, 2013)

As suggested, the journeys, struggles, and triumphs of these eight participants vary greatly. But MS has had a large impact on all of their daily functioning, their families and relationships, their roles and functioning in society. With these back stories in mind, I will now unpack the themes identified for each of the specific questions outlined in this study: (a) how MS has affected their quality of life; (b) what role pain plays in their lives; and (c) what changes, if any, were experienced when applying the therapeutic tool of self-hypnosis?

Quality of Life

A semi-structured interview was used to address the first topic of investigation of how MS affects one's quality of life. There is no universally agreed upon definition for *quality of life* (King & Hinds, 2003), as it is a very personal and multidimensional construct. The participants were asked to first define what quality of life meant to them. These definitions not only varied per person, but the definitions of each individual were multifaceted, complex, and often vague. Most participants reported that their idea of quality of life changed both in definition and measurement; by the day – and sometimes hour. All participants reported that their quality of life has been shifted by MS, and some reported that it has shifted both for the negative and the positive. Four main themes emerged in defining and measuring one's quality of life: (a) connectivity with others, (b) level of functioning, (c) positivism, and (d) hope. The unpredictability of the disease was addressed by eight out of eight participants and reported by almost all to affect each of these four thematic domains.

Connectivity. The level of feeling connected with others was addressed in one form or another by all eight participants and highly prioritized as a deciding factor for them feeling a high quality of life. Being able to be an active member of the family, friendships and/or community was reportedly essential to feeling fulfilled and happy. The ability to physically and emotionally help others was reported to increase one's quality of life by six of the eight participants. Quantity and quality of time with loved ones was reported not only as an achievement of a higher quality of life, but also a gauge. One participant explained:

I think that I measure [quality of life] a lot based on my son and my relationship to my son and what I can do with my son, and what I can't. I think that my family and how much my husband has to step in to help out, or whether I can be a productive part of our family unit, is probably how I measure quality of life.

(208, personal communication, September 19, 2013)

Those who reported that they felt their illness has prevented them from being actively connected to- and engaged with- their loved ones reported feeling a jeopardized and substandard quality of life. This forced segregation from others and diminished quality of life was reported by three participants as a dominant way that they felt tormented by their MS. Three participants reported mourning the quality of life taken by MS through the loss of their ability to contribute, which they explained left them feeling unfulfilled, unhappy, and of diminished worth. One participant disclosed:

I feel like [MS] has robbed me of the quality of time and the quantity also of being with my two children...it's so difficult for me to travel...and even when I do go there, everybody lives in these huge homes with stairs after stairs. I can't stand up and hold the babies [her grandchildren]. To me, that's quality of life – holding them, touching them, and going outside and being the grandma and all that...[starts to cry and apologizes for her emotional response]...the quantity, I have everything, but the quality is so diminished...I just feel totally separate from everything that's going on in any occasion...like I said, I feel my life has lost all of its quality and that's kind of where I am. (203, personal communication, August 2, 2013)

Another participant shared how her MS gave her only short windows of time on random good days when she could feel functional. She too expressed feeling excluded from a conventional life and segregated from her loved ones:

My husband does a wonderful job of helping me, but I feel like I'm not being a part of the family at times, so I'm very frustrated with that part...I just think being with family is so important and I'm missing a lot of that...I was lying in bed yesterday thinking I have friends that are kayaking and at the exercise gym and here I am lying in bed and my husband's downstairs having dinner by himself. That's overwhelming. That's not quality to me. I want quality! I want to be relaxed. I want to be stress free. I want to be healthy. I don't want to have to deal with this. I don't want to have anybody else have to deal with this, and especially not my family. (206, personal communication, August 7, 2013)

Another participant explained how being an active reciprocal part of his personal community enabled him to experience a higher quality of life:

Having friends, and just being part of the neighborhood to help out, watch out for the neighbors, and do what you can to help the neighbors. That's me. That's quality of life, helping out where you can help out; somebody to just be helpable. Hopefully it'll turn around and come back to you in its own time. (201, personal communication, August 2, 2013)

Although the specific roles and relationships varied, each of the eight participants agreed that being free to have and engage in active, intimate and balanced relationships with the people that they value was among the predominant qualifiers for a high quality of life. The level of feeling connected with others, being an active member of their

family and/or community, having the ability to assist others, have quality of time with loved ones, and fulfill their roles as parents/grandparents/partners was identified as the more important factors in quality of life.

Level of functioning. All eight participants referenced their level of functioning as a determiner for their quality of life. Where seven out of the eight referenced a physical level of functioning, both the cognitive and emotional level of functioning was stressed by almost all participants as well. One's level of functioning not only determined one's ability to be independent and care for themselves, but also to gift them with the ability to care for others as well.

Seven of the participants had children, ages from birth to adult; two shared that they were also grandparents. The ability to function at a level that allowed them to take care of their loved ones in a range of ways (from bathing and feeding them, playing with them, and assisting them with home improvement projects) reportedly had a direct impact on their quality of life. These participants all reported feeling more fulfilled in their roles as parents/grandparents, but also fulfilled in their quality of life when their bodily capabilities matched their desired level of a fourth step was applied to the most data-rich case. functioning. On the contrary, when participants' symptoms interfered with their ability to be independent and/or fulfill these roles – their quality of life was reportedly poor. One participant shared, “quality of life for me is being able to do the things that I want and need to do for myself and for my family,” (202, personal communication, August 2, 2013), and when her MS would drastically flare she recalled, “I felt like my quality of life was poor because I just felt like I couldn't do anything, I just felt horrible!”

Many participants spoke to how their productivity was greatly reduced by their MS. Five reported that productivity, even at the most basic of levels, has been greatly altered by MS in that merely getting themselves out of bed and ready to face their day could reportedly be a large feat. Seven participants discussed how daily functioning would require them to plan and strategize to divvy their energy and resources; even then, their productivity and functioning was greatly reduced, slowed, and even halted at times. One participant conveyed:

Honestly too...I'm tired. I'm so physically and emotionally just tired of dealing with it every day, waking up every day going, "oh man, here's another day of MS. Let's get out of bed, and let's go pee a hundred times and hope you can make it to the bathroom." Here's the deal, it's just so exhausting that there are literally times that I'm serious, I don't leave the house for two weeks at a time...I'm just...I'm done. I'm fried, and I just lock myself in, and I just am tired. So it's been probably over 40 years [as she reported having symptoms since childhood] I've had it, and I'm just tired. (203, personal communication, August 2, 2013)

Another participant expressed:

[MS] controls my day, controls everything I do. It makes me have to plan around it – if I can. Some days I sleep for a day just to do lunch with a girlfriend. Emotionally, it's so frustrating! I feel sad about that a lot. I just want it to go away! (206, personal communication, August 7, 2013)

Level of functioning, physically, cognitively, and emotionally, greatly impacts one's quality of life. MS was reported by all eight participants to affect their level of functioning in at least one of these domains, if not all three.

Positivism. Perspective appeared to be a large determinate for one's quality of life. One's ability to focus on the things that he/she is grateful for appeared to have a positive impact on the reported quality of life for half of the participants. One participant noted, "[Quality of life is] what you make of it...you get up in the morning, your feet hit the floor and not your face; you're looked at and not viewed - that's good quality right there," (201, personal communication, August 2, 2013). Another participant reported that her quality of life was improved "by focusing on what [she] can do and not looking at what the disease takes away. Being grateful that [she] can still walk and that [she has] opportunities that other people with MS don't have," (205, personal communication, August 7, 2013). Six of the eight participants explained that it could be worse, for instance they could have cancer, be immobile, be in more pain, etc. Where the above illustrated positivism is a form of coping, it emerged as thematic to helping this population live a higher quality of life with MS.

Hope. Hope was specifically addressed by name, by only one participant. He shared:

I guess I would define quality of life with happiness and sort of a hope, a hope of the future, a hope of ... Yeah, because I do think MS plays into your future, because it is an unknown factor. It makes it really challenging, so I think that to be hopeful is something that people take for granted, but it's something that I strive for, it's just to project into the future, and being healthy. That can mean anything. Health is different to different people, but I feel it's important. (204, personal communication, August 2, 2013)

Hope was included in this list of themes because compromised hope clearly played a large role in the quality of life of all of the participants. Even the few participants who reported a positive outlook still referenced a looming fear and anxiety of when and how their MS would finally catch up to them and destroy their bodies and deplete their quality of life. Those participants who identified that MS had already robbed them of their independence, mobility, connectivity, and functioning already reported hopelessness and desperation. One participant shared of how her diminishing hope left her avoiding new potential treatments and relief from her symptoms for fear of running out of options:

I almost feel like...oh, maybe this will work, and it will kind of be a last resort because after that, there's really nothing, so I guess I won't try it, maybe in the hope that down the road I'll try it, and it will still leave me an option. (203, personal communication, August 2, 2013)

There is no agreed upon definition of quality of life; however the prominent themes in the stories of these eight people were an emphasis on connectivity, level of functioning, positivism, and hope. Connectivity with others, including being an active member of their family and/or community, having the ability to assist others, having quality of time with loved ones, and the ability to fulfill their roles as parents/grandparents/partners was identified as being among the predominant qualifiers for a high quality of life for these participants. One's level of physical, cognitive, and emotional functioning was found to greatly impact one's quality of life as well. This includes one's ability to be independent and care for themselves and others, as well as

his/her general productivity. Positivism and hope, whether existent or not, was also found to considerably affect the quality of life of each participant.

Role Pain Plays

The second topic of investigation explored what role pain played in the lives of these participants. Seven out of eight participants reported feeling daily physical pain. The semi-structured interviews revealed that pain held strong physical, mental, and emotional implications for seven of the eight participants, and had a profound mental and emotional impact for the remaining participant. Three main themes emerged when explaining the role of pain in their lives: (a) physical torment, (b) mental consumption, and (c) emotional inundation. The role and impact of pain is not easily separated into the three categories of physical, mental, and emotional – as each category inter-relates and greatly affects the others, so some overlap is present in the following.

Physical torment. Physical pain was reported to be central in the life of four of the participants, and present daily for seven. Void of medical intervention pain was reported to be debilitating for three. One participant reported, “I usually have a TENS [Transcutaneous Electrical Nerve Stimulation] on my lower back just in order to survive or do things,” (201, personal communication, August 2, 2013). Another participant recounted:

The last eight days, I had this excruciating pain in my face that started about nine years ago just in my lip and it felt like the worst part of coming out of dental surgery, you know, where the numbness is going away and the gross stuff is coming back. But, it’s excruciatingly gotten worse and much more intense, to the

point where I just cry. I want to go to the hospital and get a pain shot or something. (206, personal communication, August 7, 2013)

With the unpredictability of MS, two participants shared how pain is the only daily, reliable thing that MS gave them. “Physically, it controls my day, controls everything I do” a participant (206, personal communication, August 7, 2013) shared. Another participant explained how MS has led to a chain reaction of ever-increasing negative physical impacts on her body:

[I] have pain every day, probably most of it attributable to the MS. Some of it I think because of the MS has led to other things like the gait is off, so I’ve had four back surgeries, and the gait is off. It’s caused hip problems, and I had to be on chemotherapy once for the MS, so it caused neuropathy, so a lot of the pain is related to MS, but the MS pain is there; the numbness, the tremendous numbness. I get the tightness in my throat. Sometimes everything just zaps like an electrical current. (203, personal communication, August 2, 2013)

Many of the participants reported suffering from relentless pain, “Pain is killer on me!” one participant (201, personal communication, August 2, 2013) shared, and another reported:

My head hurts constantly, yes, and that is really the biggest pain. Sometimes, I’ll have issues where it feels like pins and needles on the feet, and hands and stuff, legs, but that usually passes but the head pain never stops. (202, personal communication, August 2, 2013)

This constant pain has led to a certain degree of acclimation to the pain. Five participants reported that they felt they have gotten used to the pain in a way, “Physically, I’m getting

so used to it, it's like I wouldn't know how to feel if I didn't have pain every day," one participant (203, personal communication, August 2, 2013) stated. Another participant shared:

I don't know if it's just that I've gotten used to my legs being in pain, so therefore I don't think about it, and when I do, then I'm like, "Oh, yeah. My legs hurt", or that it's actually gotten less painful and I'm just noticing. (204, personal communication, August 2, 2013)

Another participant further explained that she often only realized her level of pain once her emotional response has gained her attention:

When I stop and look at it for me, I don't register that I'm in pain a lot of the time, but I'll be super irritated with everybody. Then if I stop and think, "why is everyone so irritating right now?" that's when I realize, oh, it's because I'm already right here [holding hand in front of forehead, signaling a level], because I'm coping with the pain. (208, personal communication, September 19, 2013)

The participants further shared that they would often tune the physical pain out and keep going, but their emotional response to it reportedly varied greatly. In addition to adjusting to pain being one's baseline, another participant shared that the way in which she perceived pain had also changed, "I almost think since I've been diagnosed my pain level has shifted and so I don't experience pain the way I did prior to my diagnosis. There is a certain level of discomfort that I live with pretty much," (205, personal communication, August 7, 2013).

The specific pains of each individual varied greatly, however the impact that pain had on the participants' life was similar in that most suffer from unyielding pain that has

altered their perception and become their new baseline. This adaptation, however, has led to further implications of the participants not always being aware of their level of suffering.

Mental consumption. Pain reportedly consumed and taxed the mental resources of six of the participants. As expanded upon earlier in this chapter, many of the participants reported that their day to day life required tedious and intense planning (e.g. to avoid heat, to conserve physical, mental, and emotional energy, to avoid potential flares, to navigate through the physical demands of an environment, etc.), resulting in pain being mentally exhausting. Pain would reportedly become all-consuming at times, therefore interfering with daily functioning. One participant explained:

I think that as far as mentally goes, I think that it's like it takes your focus away sometimes when all you can think about is like “ouch, ouch, ouch,” like it's hard to focus on anything other than that. That's not very fun to have that just constantly in your mind. (202, personal communication, August 2, 2013)

Cognitive interruption was reported as a pain by three participants; two of these participants required frequent redirection to keep on track of the interview or their thought processes. At one point in the conversation when a participant had lost track of the dialogue, she shared, “Part of the pain for me is things like what’s going on right now, I just can’t process and that really bothers me!” (206, personal communication, August 7, 2013). Another participant stopped mid-sentence to report, “I have a lot of pain and so I lost my train of thought,” (208, personal communication, September 19, 2013).

The participant who reported no current physical pain reported that he struggled greatly with mental pain in the forms of memory problems, tension, and depression:

“Mental pain is something this is a major struggle for me...I can't seem to break free from it,” (Participant 207, personal communication, August 19, 2013).

Three participants emphasized that they spent a lot of mental energy and time comparing and analyzing their experienced pain with the pain that they understand others to endure. One participant disclosed:

I think about pain A LOT and I think about not just the sensation of pain but trying to figure out what levels of pain other people are living at...so yeah, I spend a lot of time trying to figure that out...so I spend a lot of time trying to compare and analyze it. (208, personal communication, September 19, 2013)

Additionally five participants reported that they struggled to maintain a balance of how much mental energy was absorbed by their physical state. One participant shared:

I personally feel like I'm focusing way too much time on being not well and I want to shift that focus on to the well part, because I believe our mind really plays a major part in how I feel and I feel I'm losing that. (206, personal communication, August 7, 2013)

One participant shared how keeping a pain diary in the past had actually intensified her pain, leading her to discontinue this form of journaling:

I filled out a pain diary. It's cool. With iPhone there's apps you can get that remind you to do it, so I filled it out and decided I had to stop because I think I did it for three months, and in those three months I only had a couple of days that were a two. Other than that, everything was like an eight, a seven, a six, and it was focusing on that what seemed to make it worse. It seemed like the more I

looked at it, the more I could feel each sensation of pain as opposed to focusing on what things feel good. (208, personal communication, September 19, 2013)

Pain was reportedly mentally consuming for six of the eight participants, forcing them to plan, change behaviors, and for some, strain to think and interact at their former level. Additionally, when pain absorbed these participants' mental attention, the physical pain was reported to intensify for some and further negatively impact his/her quality of life.

Emotional inundation. Pain was reported as emotionally taxing by all participants. The emotional component of pain is multifaceted, themes of desperation, helplessness, fear, self-loathing, denial, difficulty accepting, loneliness, depression, anxiety, anger, and exhaustion were found. A painful disease that provides little predictability can often result in desperation for reprieve, for not only relief, but also answers. One participant revealed:

Emotionally, it's exhausting to hurt. Sometimes, people stub their toe, or break a leg or whatever but eventually, it all feels better...and it's just annoying to think that it [referencing constant migraine] might not. I was at the neurologist this past week and I was just like, "Is it always going to be this way? Is it ever going to stop hurting?! Like my head, will it ever...?" and he's like, "It may, or it may not. I don't know, I wish I could tell you but I have no idea." He's like, "You really can't predict things like that." I hate that answer...I hate it! (202, personal communication, August 2, 2013)

Where almost all of the participants reported that MS was a disease that required constantly renewed acceptance (e.g. as their mobility decreased, new devices or

medication were required, new symptoms emerged, etc.), only three participants admitted to sometimes falling into a state of self-loathing, some even actively denied it. One participant shared:

Physically it's a pain in the ... [word not verbalized], mentally it's like "damn, when's it going to go away?" Emotionally, it's the question of "why me?!" ...The "why me?" ...that part's gone. They still come and go, but why it happened to me? Shit happens, period. (201, personal communication, August 2, 2013)

Another participant expressed:

It's like I don't know, the whole pain thing emotionally has been really difficult because there are days that are like, "why me?" And nobody understands...and I won't talk. It's like I will talk about it with people but then I get that [sympathetic] "ohhh," which I don't cope well with. So I'll talk about it if it gets really bad and I just need people to give me some space, I'll then let them know so that they can give me my space...So, emotionally it's been difficult. (208, personal communication, September 19, 2013)

Being emotionally overwhelmed and feeling unable to share it with the people in their life was expressed by six of the participants. The isolation of MS became transparent as the participants expressed that they felt both unable to articulate themselves, as well as frustrated that others lacked the capacity to truly understand them. Furthermore, pain reportedly often made interacting and tolerating others more challenging as their physical complaints felt minimal in comparison to the woes that the person with MS was working diligently to manage internally. One participant shared:

Physically it's often at a point where I can turn it off and keep going.

Emotionally it depends. There are times that it's like, "it's not fair!" People will be like, "oh I have a crick in my neck I must have slept wrong," and they

complain about it all-day-long, and I just want to scream: "You have no idea!!"

So it depends. If I'm having a good day it's not that big of a deal, it just is what it is and I do all of those things. (208, personal communication, September 19, 2013)

Two participants spoke at length to how the pain made it hard to differentiate physical from emotional torment as the pain was so overwhelming and all-consuming.

One participant expressed:

Psychologically, I get so angry about it that I just can't differentiate anymore what's real, what's not. It's just all jumbled up. It's just pain. I'm in pain all the time, so it almost doesn't matter anymore. (203, personal communication, August 2, 2013)

The helplessness that two participants shared included both their own personal feelings of helplessness, as well as their recognition that the medical professionals too were helpless when confronting this disease. One participant disclosed:

When I go to the doctors and they say, well, where are you hurting? It's so funny. It's either they want to attribute everything to the MS and just ignore it; "it's just MS," or it's an actual issue, but they almost don't want to deal with it because they know it's attributable to something caused by the MS. So I'm kind of in a limbo thing with the pain. (203, personal communication, August 2, 2013)

The limitations that MS placed on the roles and functions that participants were and were not able to fulfil also had a grave negative impact on the emotional state of five of the participants. One father spoke to how his limitations from MS mentally and emotionally taxed him as he was unable to fulfil the role of a father to his desired level:

It plays a role in all three aspects, I guess. Physically, I'm tired. I have little kids. I have a three-year-old and a two-year-old and a baby that's going to be born in the next two weeks. Their expectation for dad is very different than what I physically can do at times; that sort of transfers into mentally. I don't feel great when I can't run around with my kids. (204, personal communication, August 2, 2013)

As highlighted prior in this chapter, four out of six participants reported having forms of regret and guilt for the different burdens that their MS had on their partners and/or children. Whether their young children were taking care of themselves (and at times their parents), their partners were chauffeuring them from appointment to appointment, their loved ones would go without, or their partners would get the emotional backlash of their illness, the emotional burden of MS was reportedly heavy for some. One participant shared:

Then of course, emotionally, luckily for the outside world, it's my wife that gets most of the emotional backlash of me not feeling well. I think that it's unintentional with that. I explain to her why I react that way or why I get frustrated and that I'm not frustrated with her, but she's the only person that I really feel like has a day-to-day understanding of what I go through and how it feels. It sort of comes out that way. I would say it's like pain manifests

physically, but it runs the gamut. It's not limited to just being in pain. (204, personal communication, August 2, 2013)

The emotional component of pain was reportedly complex, but appeared to have a considerable impact on all participants.

Pain had a profoundly negative and convoluted impact on the lives of these eight persons with MS. The physical, mental and emotional constituents of pain each had a reportedly drastic impact on participants' existence, and the combination was reportedly devastating for some. Based upon the collected data, all three elements of pain must be taken into account in order to gain a complete picture of how pain impacted these participants' lives. Pain was found to be physically tormenting, mentally consuming, and emotionally inundating for these persons.

Experiences of Self-Hypnosis

The final topic of investigation addressed what changes, if any, were experienced when the participants applied the therapeutic tool of self-hypnosis. The data used for this section was collected after the participants had engaged in four weeks of self-hypnosis and through the means of both their completed journals (one entry per week), and a final survey. Four main themes emerged from these sources of evidence: (a) improved emotional regulation, (b) intrapersonal improvements (c) improved cognitive functioning, and (d) improved physiological state. Seven out of the eight participants submitted their journals and surveys so the following section will be referencing a sample size of seven participants. The eighth participant (206) was unable to complete the study due to health reasons.

No negative or adverse effects were reported by any of the seven participants. Six of the seven participants experienced various positive changes through the use of self-hypnosis; the remaining participant reported no changes and expressed that he was unable to experience the self-hypnosis via the pre-recorded scripts. During the orientation meeting, a sample listening activity was performed and all of the participants were asked to close their eyes and follow along with the guided instructions. The activity directed them in a brief breathing exercise which also increased their bodily awareness and guided somatosensory changes (e.g. feeling the weight of their bodies sinking into their chairs, etc.). In his journal, this participant shared:

I did not have any success with the tapes...When you spoke in the room, I felt myself sinking into the chair and it worked! But listening to you on the tapes is not doing anything yet. I listen to talk radio all the time so that might be part of the problem. (201, personal communication, October 19, 2013)

Although this participant listened to the scripts more than any other participant, for a total of 30 times (group mean = 17.25), he reported no success. The following sections will focus solely on the changes experienced by the remaining six participants as participant 201 did not experience success with self-hypnosis and did not report any changes or experiences.

Improved emotional regulation. The experience of physical discomfort can result in emotional dysregulation as many participants reported that their physical pain would make them feel as if they mentally and emotionally spiraled out of control in a negative chain reaction. One participant explained, “Along with the pain comes agitation, which then leads to guilt over feeling like I have wasted time being frustrated

and/or agitated,” (202, personal communication, October 21, 2013). The anticipatory anxiety over the specific course and effects of MS reportedly affected all participants due to the unpredictability of the disease. Five participants reported various improvements in their ability to regulate their emotions during the course of the four week intervention including reduced levels of anxiety, increased calm, increased relaxation, and reduced stress.

A reduction in anxiety was reported by four participants, not only as a general emotional level, but also in terms of facing stressful situations of day-to-day life. For instance, one participant faced traveling and preparing for a family member’s wedding and reported, “I listened to the CDs while in the hotel room and the anxiety I usually have while ‘getting dressed up’ etc. was a little less,” (203, personal communication, October 19, 2013). Another participant reported that he was “able to step back from anxiety” as well as have better “control over emotions and fear,” (207, personal communication, October 21, 2013). An increased sense of calm and relaxation was reported both as a naturally occurring byproduct of the self-hypnosis (e.g. “[I have] a better sense of calm after the sessions,” [204, personal communication, October 21, 2013]), as well as through the improvement of skills and abilities to “find calm” and “to calm [themselves].” One participant reported that he attributed his “being able to move into a place of calm” (204, personal communication, October 21, 2013) to his four weeks of self-hypnosis. Another participant shared, “When I feel the stress building up, I used some of the techniques to just slow down and relax,” (203, personal communication, October 19, 2013). In addition to the conscious level, emotional regulation also occurred on the subconscious level. For example, one participant reported, “I definitely can relax during the process

although I don't typically remember anything, which is strange to me," (202, personal communication, October 21, 2013). This is indicative that these participants' relaxation was occurring void of their awareness, let alone their conscious input or efforts.

Stress reduction was also reported by four of the participants and a "better ability to manage small stressful situations" (204, personal communication, October 21, 2013) was reported by two. Although the credit to the stress reduction was given to "breathing" by three of the four participants, it is listed here as a change reported during the exercises of self-hypnosis. One participant explained:

Regarding the stress management, I get lower back pain when I am stressed, which I got this week, but the back pain didn't linger like it normally does and I think it was because I took a few minutes to breathe if I started to stress out. (204, personal communication, October 21, 2013)

Note that because a successful application of self-hypnosis necessitates that the conscious mind (the logical and problem-solving part of the brain) is quieted, and ideally not engaged during treatment, any succeeding reflection about what caused which responses using this functioning of the brain inherently leads to a skewed presentation.

Intrapersonal improvements. Six participants reported improvement within their personal mind and self. A heightened and enhanced awareness was reported by four participants. Where some reported a "greater awareness of [their] world" (207, personal communication, October 21, 2013) and larger surroundings, others reported increased mental and bodily awareness. In the third week of administering the self-hypnosis, one participant explained:

I felt like my hand and arm felt more connected. My right hand and arm have been numb, like when your leg/arm feels asleep, for the last three years in varying degrees. So I felt a certain level of disconnect with that. After both sessions my fingers seemed better. It's really hard for me to compare how my arm feels but I thought it felt better as I went to bed. (204, personal communication, October 21, 2013)

Another participant shared of the enhanced mental awareness that she attributed to four weeks of self-hypnosis and reported, “[I gained] awareness of my avoidance of addressing my mobility issues because I was afraid of the possibility that they would not be helpful,” (203, personal communication, October 19, 2013). Another participant shared that she gained an increased awareness of her self-critical and judgmental inner voice and the ways in which it was interfering with her life, adding that through the application of self-hypnosis she “...became more aware of my critical/judgmental voice. I realized I could be an observer to it and choose to do the self-hypnosis,” (205, personal communication, October 24, 2013).

An increased level of self-confidence and a sense of empowerment were reported by five participants. Some reported an improved sense of trust in their own abilities, for instance:

I am more aware of my surroundings and how I can make them positive. It is an interesting feeling because I feel like I can deal with stress better but not feel like I am pushing it aside. I can take on stressful things with the intent to fix them instead of just ignoring them. (204, personal communication, October 21, 2013)

Others reported feeling an increased confidence in the power of their mind, one participant noted, “[I gained] a sense of well-being, knowing my mind has ability to shift the way I deal with pain, etc.”, (205, personal communication, October 24, 2013). When asked what she learned about herself in this process, another participant shared, “I learned that I can do a lot to manage my own pain without needing to use medications,” (202, personal communication, October 21, 2013).

Three participants reported increased hope and encouragement through this process. One participant shared that due to hypnosis, “I am feeling encouraged by the fact that everything is looking more doable,” (202, personal communication, October 21, 2013).

Four participants shared through the four weeks about how they grappled with internal obstacles, self-placed hurdles, and obstructions. Three participants wrote that they were challenged by their own resistance to doing something that would help them, whether it was prioritizing the time for self-care (in this case administering the sessions), or for applying other means of important changes to their lives. One participant recognized that her “resistance to acknowledging the changes in [herself, her] life” was negatively impacting her quality of life (205, personal communication, October 24, 2013). By week four, one of these participants shared, “I feel myself walking away from the door I’ve been waiting too long to open so I can welcome and accept a new door,” (207, personal communication, October 21, 2013). Where the struggles and triumphs these participants shared in the course of these four weeks are not suggested to be solely via the influence of self-hypnosis, these changes were reported and three of the four participants shared that they believed self-hypnosis had a direct influence.

Two participants reported an increased level of acceptance of both their situation and self during this four week span. In week two, one participant shared that her quality of life had been increased over the past week because:

I have accepted the fact that I have major limitations in mobility. Once I got to that point, it eliminated some anxiety. When we were on our trip we rented a wheelchair. It was as if my body just totally went into a relaxation state. (203, personal communication, October 19, 2013)

Four participants reported improved self-regulation when not directly undergoing treatment; for instance, one participant reported that by week four, “It seems that this week I have had more success in using the techniques [techniques not specified] during the times I am not listening to them,” (203, personal communication, October 19, 2013).

Four participants shared that their application of the breathing techniques helped them to cope in daily life, for instance: “When I feel triggered I start breathing in the square pattern [a breathing technique that was taught in script three entailing inhaling for four counts, holding the breath for four counts, exhaling for four counts, and holding for another count of four before repeating the process with an inhale] – even if just in my head; it helps calm me and ground me,” (205, personal communication, October 24, 2013).

Three participants shared an enhanced perspective and outlook after self-hypnosis. One participant reported after week two of treatment, “My wife commented on my general mood saying I seemed better than normal. I think that I internalize a lot so to have her notice something gives me a feeling that I am working to improve my outlook positively,” (204, personal communication, October 21, 2013). Other participants

reported a change in perspective that was more internally observed, for example one participant shared he was “laughing to [him]self about how insignificant [his] past troubles actually were,” (207, personal communication, October 21, 2013).

All but one participant reported improvement within their personal minds and selves in the areas of enhanced awareness (awareness of surroundings, mind, and body), increased self-confidence and a sense of empowerment, increased hope, increased level of acceptance (situation and self), improved self-regulation, and improved perspective and/or outlook, during the course of the four week treatment.

Improved cognitive functioning. Five participants reported improved cognitive functioning during the four week intervention phase including increased focus, improved ability to mentally and emotionally reset, improved problem solving and decision making, enhanced thought regulation, and increased productivity. Three participants referenced an increased ability to focus and become more mentally grounded through the use of the self-hypnosis. One participant shared that the sessions offered her a “sense of relaxing, a focusing mind, rather than getting caught up in thoughts...self-hypnosis can help me move from monkey-mind to a focused, centered, grounded place,” (205, personal communication, October 24, 2013).

Three participants spoke to how the application of self-hypnosis allowed them to mentally and emotionally reset; one participant explained, “this hypnosis has helped create a disconnect, almost like a temporary reset button that reduces my stress and puts perspective back into mind,” (207, personal communication, October 21, 2013).

Two participants suggested that the self-hypnosis may have assisted them with improved problem solving and decision making abilities. One participant shared:

I do not know if listening to the CDs has affected my decision making in trying to reduce my pain, but for the first time in a year, I have been wearing my leg brace.

It helps support me while walking – tremendously – and I don't know why I have put it off this long. Wow! (203, personal communication, October 19, 2013)

Another participant spoke to how tasks began to appear more manageable: “When I sat down through the session, I was able to peace the world into order and look at my tasks in a more manageable state,” (207, personal communication, October 21, 2013). This participant also reported that he “believe[s] hypnosis is a key component to the process [of change] and help meds, activities, lifestyle changes happen easier,” (207, personal communication, October 21, 2013). “Problem solving” and “decision making” affect the course and action of change.

Three participants pointed out that hypnosis gave them an increased ability to control their thoughts – this thought regulation enabled them to not only self-soothe and decrease anxiety, but also to decrease rumination, which resulted in improved functioning, both in daily activities and in their efforts to sleep. One participant shared in his journal entry from the first week of his challenges and successes with the process of self-hypnosis:

The challenge was to move out of my internal dialogue. I really had a hard time focusing on the process instead of drifting off. By the third session I was able to go deeply into the session and didn't really realize that I was focused on the task at hand. (204, personal communication, October 21, 2013)

An overactive mind can often distract from participating in both active and calming activities. Three participants reported that they found the sessions helpful, even

when their active minds prevented them from engaging in the form in which they had desired (e.g. relaxed, quiet mind, etc.). One participant disclosed, “I did struggle to focus when I was listening this week but found that even not having complete focus I was still able to have an overall positive experience,” (204, personal communication, October 21, 2013).

Increased control over the mind appeared to enhance the quality of life of participants. In week three, one participant shared:

I think that using self-hypnosis has given me a calmer mind and allowed me to be in the moment more. My overall feeling is more positive and I don't feel as much stress for things that are outside of my control. (204, personal communication, October 21, 2013)

Additionally, two participants reported an increase in their productivity over the course of the four weeks; “I am being much more productive with my time” one participant (202, personal communication, October 21, 2013) shared.

Cognitive improvements were reported by five of the seven participants after engaging in self-hypnosis which included: increased focus, improved ability to mentally and emotionally reset, improved problem solving and decision making, enhanced thought regulation, and increased productivity.

Improved physiological state. Six participants reported an improvement to their physiological state, as exhibited by an altered experience of pain (e.g. pain relief, increased tolerance of pain, changed perception of pain, etc.), improved sleep, increased energy, increased comfort, and improved use of breathing.

In addition to the four journal questions which included three open-ended prompting questions, (What were your challenges and successes with the process of self-hypnosis this week?; What changes, if any, are you experiencing from hypnosis?; and What do you feel has affected your quality of life over the course of this last week?) and one miscellaneous question, each of the four journal entries included a section where each participant was asked to numerically rate their pain at its *worst* and *least* on a 10-point Likert scale within that same time period. See the following figures for an illustration of these results.

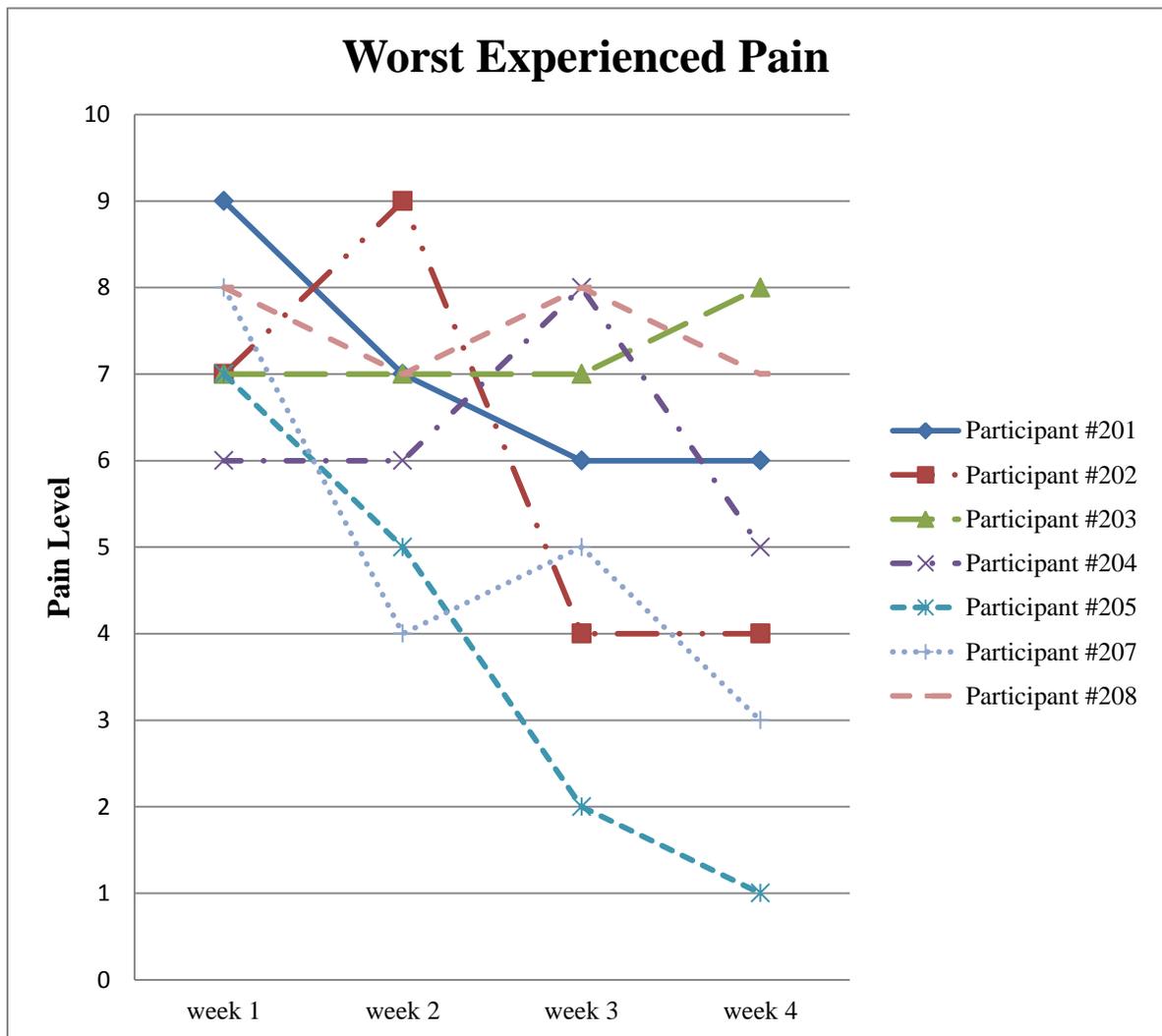


Figure 1. Seven participants’ reported “worst” experienced pain for the four week trial.

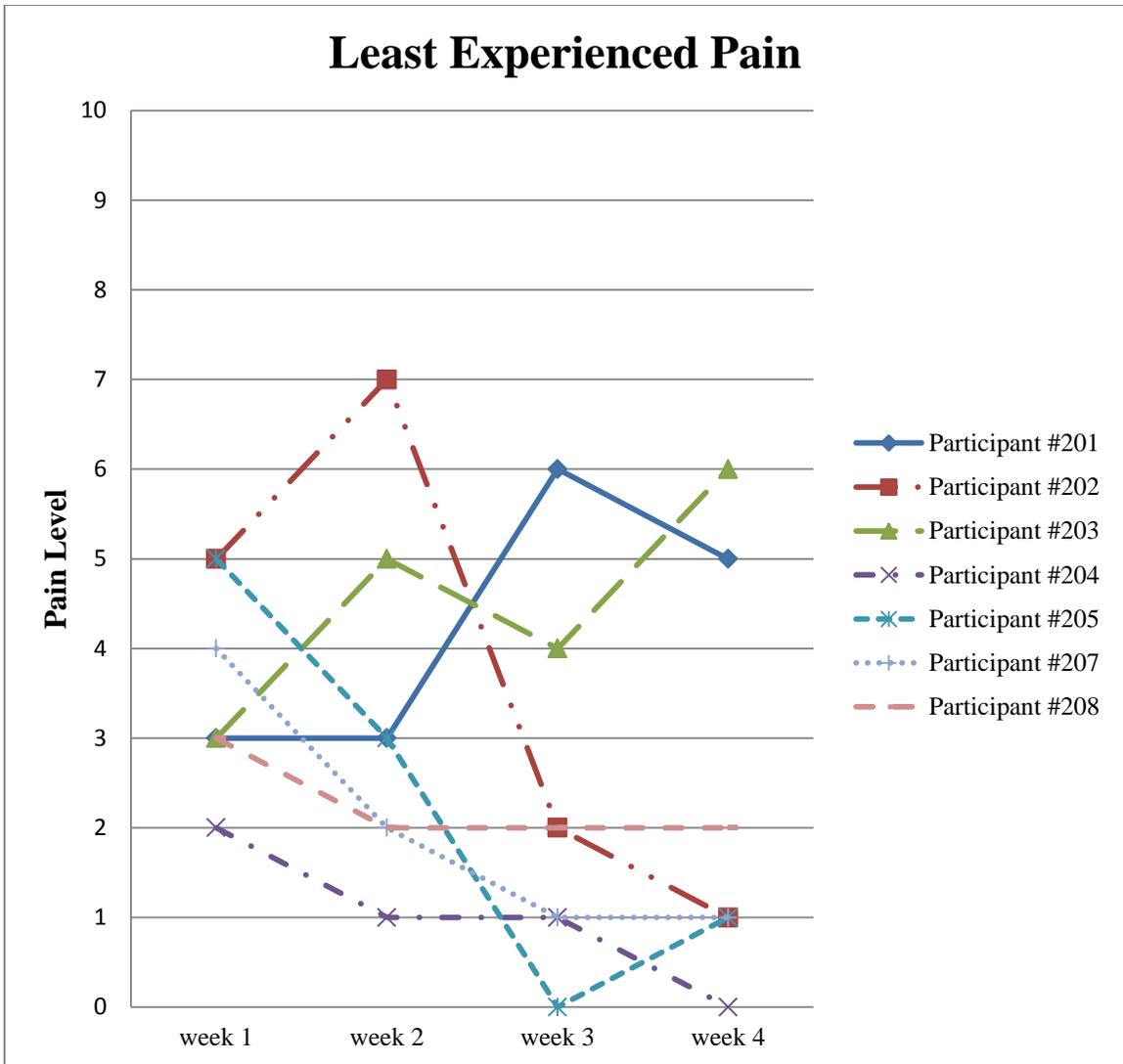


Figure 2. Seven participants' reported "least" experienced pain for the four week trial.

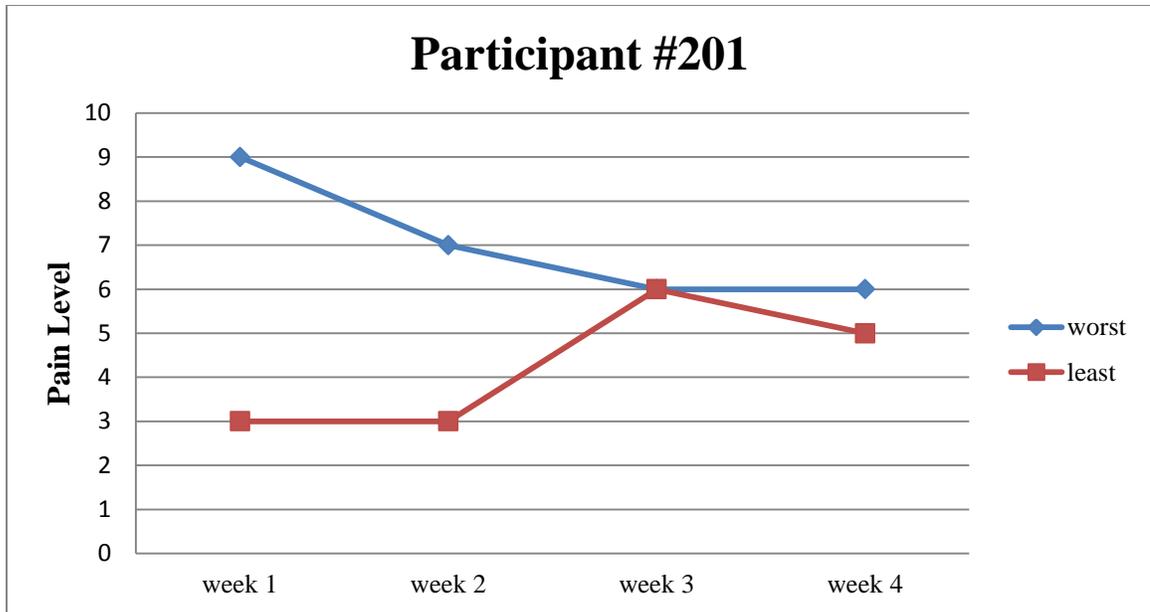


Figure 3. Experienced pain level over the four week trial, participant 201

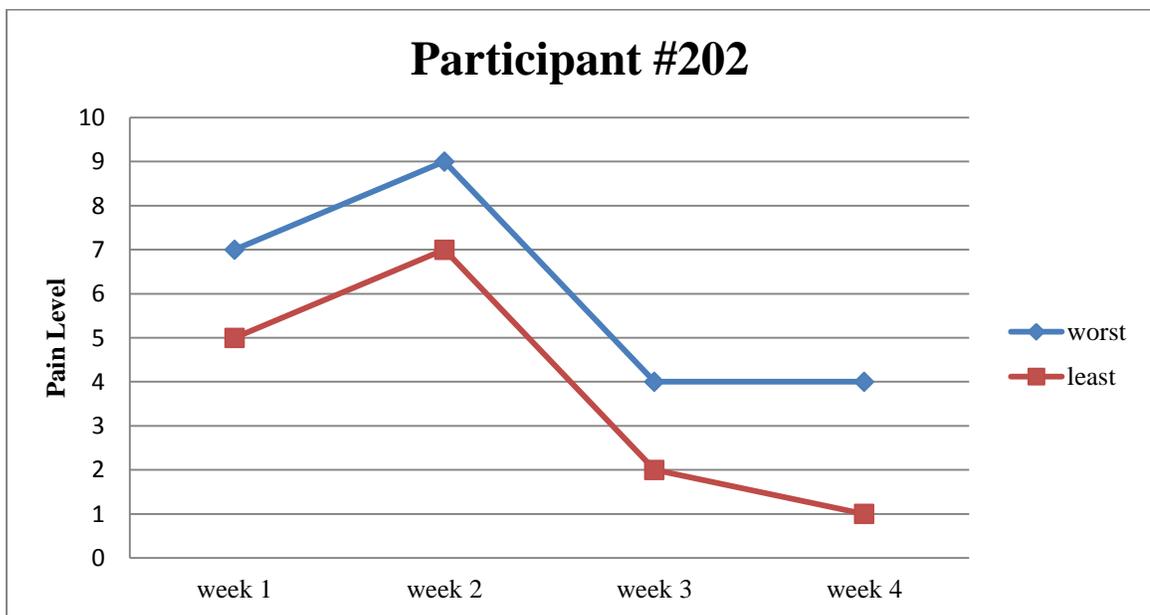


Figure 4. Experienced pain level over the four week trial, participant 202

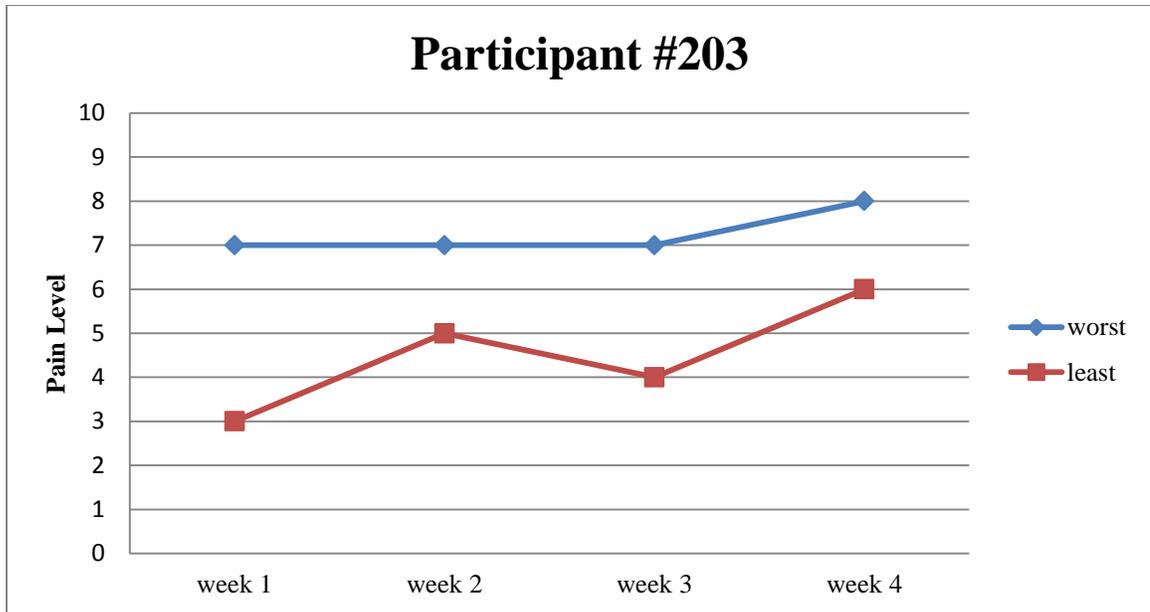


Figure 5. Experienced pain level over the four week trial, participant 203

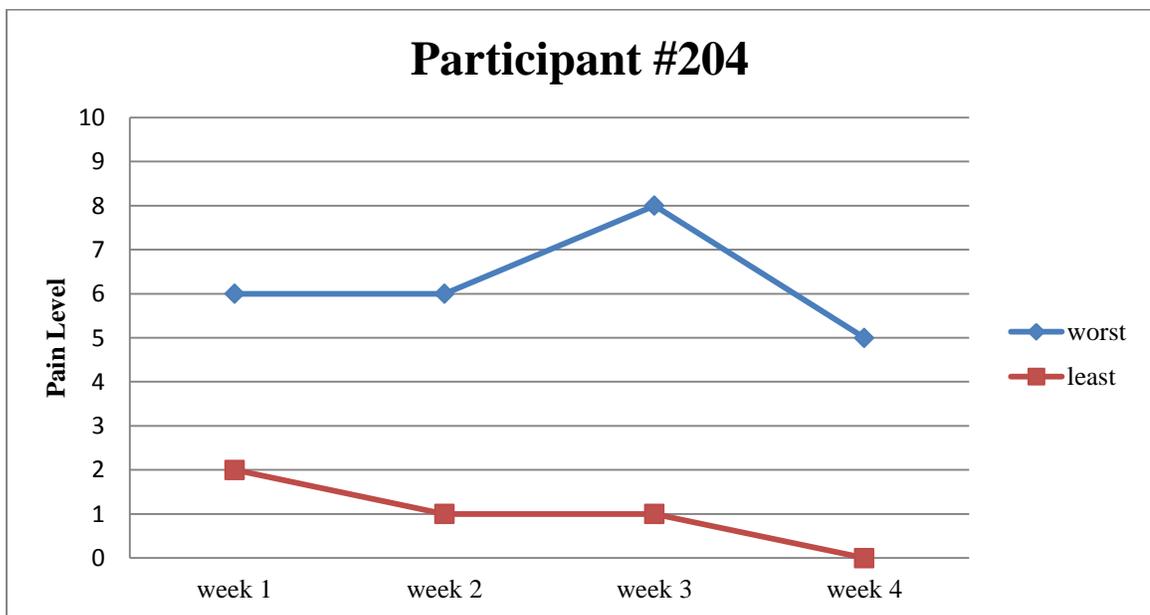


Figure 6. Experienced pain level over the four week trial, participant 204

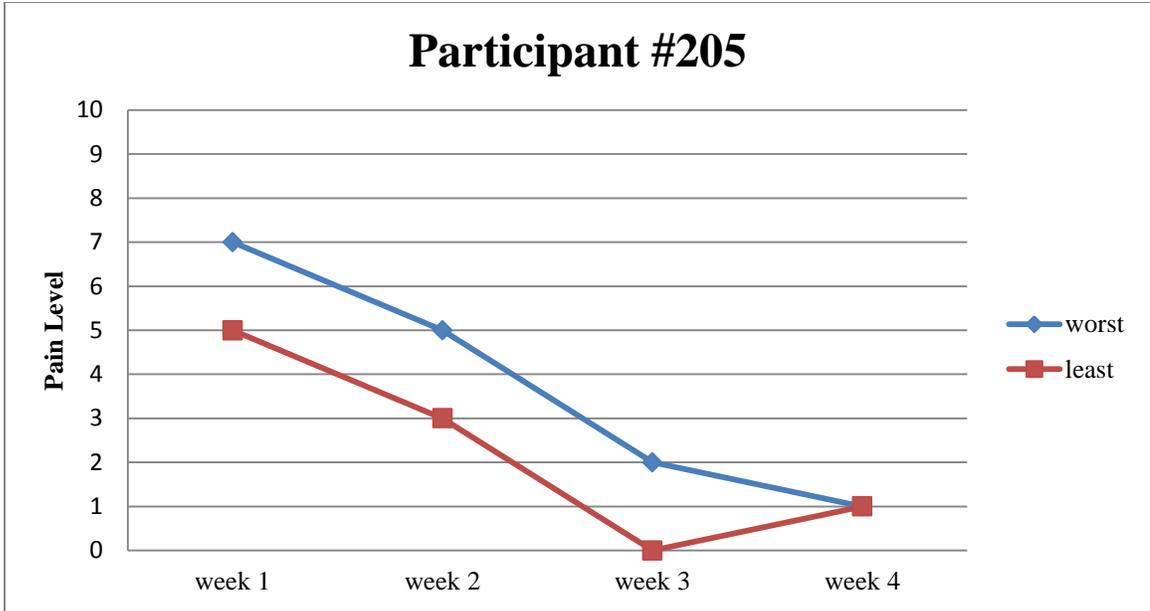


Figure 7. Experienced pain level over the four week trial, participant 205

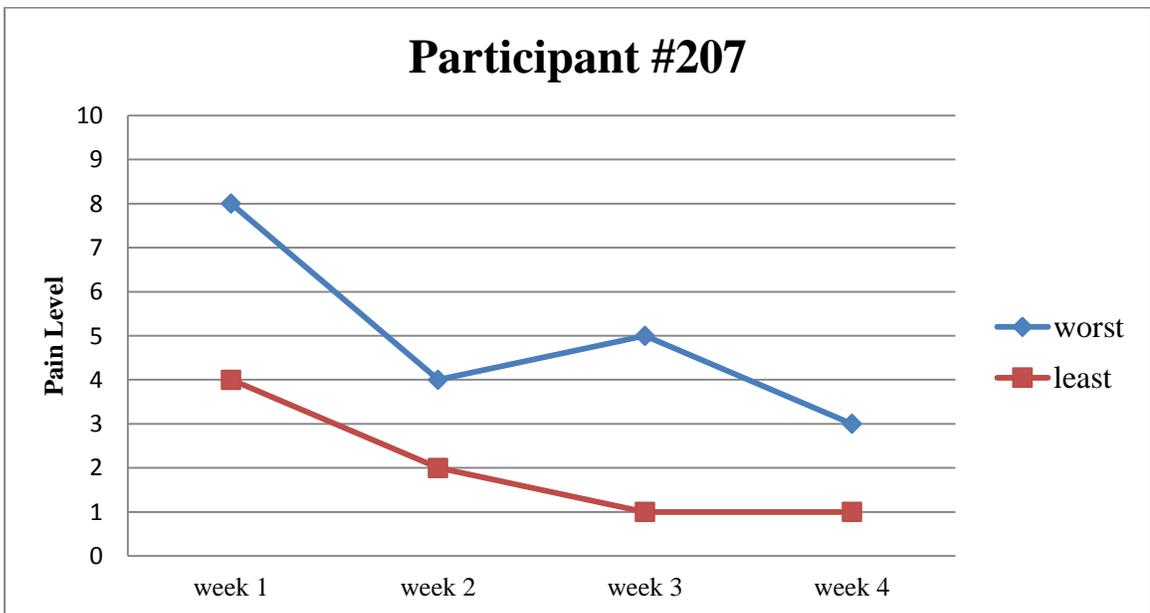


Figure 8. Experienced pain level over the four week trial, participant 207

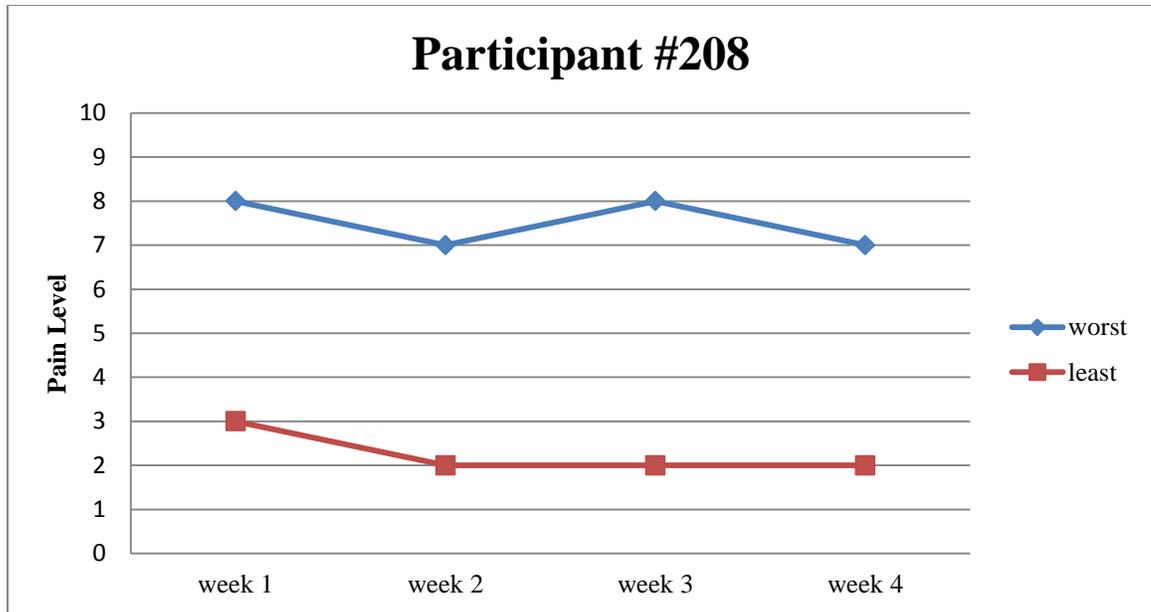


Figure 9. Experienced pain level over the four week trial, participant 208

Four participants reported a reduction in pain in their journals. Where two identified this change as diminished pain, the other two reported an increased tolerance and a decreased urgency to their pain. A few participants reported an increase in their pain levels at certain points in this study. Potential contributing factors were reported, for example participant 203 reported a drastic increase in mobile activity and travel on week two that could have exacerbated her pain levels on week three (personal communication, October 19, 2013) and participant 208 reported that self-hypnosis was effective until her hormones fluctuated around her menstrual cycle (personal communication, October 24, 2013). However, it is beyond the scope of this study to explain causes for any increases or decreases in pain levels. It is important to note that where it is unclear what caused participants' increase in pain (e.g. activity level, hormones, MS flares, etc.), the reverse is also true in that it is unclear what led to any decrease in participants' pain as well.

Participant 202 (see Figure 4) reported consistent progress over the course of the four weeks. At week one she reported, "After the hypnosis I notice definite difference in

my pain. It doesn't take it away completely, but some relief is great!" (personal communication, October 21, 2013). She continued to attribute her reduction in headaches to the hypnosis, "My head hurts far less this week [week three]. I can only attribute this to the hypnosis – so that's great!" In week four she shared, "My head pain is about the same as last week at its worst, but it's actually resolving to the point of no pain, which is huge! Oh, what a feeling!" (scaled at worst = 4; least = 0-1). This participant then reported that these changes had increased her quality of life, adding that "the fact that my head doesn't hurt at all at some points has majorly impacted my life in a positive way. It makes everything else easier to endure!"

Participant 204 (see Figure 7) reported in week four, "I felt better this week. My legs were not as painful as usual," (personal communication, October 21, 2013). Another participant (see Figure 5) shared that she felt an increased ability to tolerate her pain (203, personal communication, October 19, 2013). In week one she reported, "physically, I can't tell much difference in the level of pain. I do, however, find that the deep breathing seems to make the pain more tolerable," by week three she shared how this perception of pain had altered, "My pain is still there, but I am able to redirect my thoughts from that while listening to the CD. Sometimes the pain seems less after a session, but slowly returns."

One participant (see Figure 10) explained how her pain felt less urgent and of a different quality than before the use of the hypnosis, she shared:

It is possible that though I still experience pain as often as before I started, the quality of pain seems somehow less urgent. I have been feeling more fatigued

than in pain, which isn't ideal, but it's nice to be perceiving a possible change in the quality of it. (208, personal communication, October 24, 2013)

Six participants reported improvement in sleep, including an improved ability to fall and stay asleep, better overall sleep quality and waking more rested, and an increased ability to fall back asleep (faster and at all) in instances of premature waking.

Participants reported an increased ability to fall asleep faster and a sense of better rest while asleep. One participant reported, "The nights I listened, I fell asleep quicker and felt more rested," (204, personal communication, October 21, 2013). By week two, he reported, "I felt like my positive physical feeling lasted longer into the night which helped me sleep better", and by week four he explained:

I felt like I was sleeping better even though I slept the same amount as usual.

While I fell asleep I wasn't running through random thoughts. I focused on breathing and a positive place which, I think, improved my ability to shut down for bed.

In addition to improved sleep, one participant reported an increased ease in waking up, "I have had an easier time waking up despite the intense headaches," (202, personal communication, October 21, 2013).

Five participants reported that they felt it was difficult to not fall asleep during the self-hypnosis sessions. In week one participant shared:

[Not] falling asleep was a challenge, but a welcome one! I still have not listened to a whole session without falling asleep...which has come in handy on the nights that I woke up in the middle of the night because of pain...Great tool for sleep on

nights I would usually be up all night. (208, personal communication, October 24, 2013)

The sensation of falling asleep while undergoing hypnosis is common, and although people may feel asleep, in most cases they are not (Barabasz & Barabasz, 2008; Olson, 1984). Barabasz and Barabasz (2008) explained that from a neuroscientific standpoint, people in a state of hypnosis are focused, conscious, and alert. In week three this same participant reported that she listened to the recorded session with her child and where they had both fallen asleep, the participant later woke on cue at the point of the recording where the speaker gave her permission to wake if need be (versus drifting off to sleep) (208, personal communication, October 24, 2013). She then reported that this was the first time that she had ever heard that portion of the recording. This incident speaks to the likelihood that where one may feel as if they are asleep, he/she is still awake and aware of their intents and surroundings.

Two participants reported an increase in energy over the course of the four weeks and shared that this had a positive impact on their quality of life. One participant shared, “I think this week brought my level of quality up. I was happier and more willing to do all the physical things my kids want to do,” (204, personal communication, October 21, 2013). Another participant reported that over the past four weeks, she attributed “A change in attitude, comfort, and energy,” (202, personal communication, October 21, 2013) to hypnosis.

Four participants emphasized breathing as a positive change that they experienced over the course of the four week intervention. Pain, stress, anxiety, and discomfort are all often correlated with poor breathing patterns. Where it is common to hold one’s breath

when in pain, stress, and anxiety can often result in shallow, rapid breathing. Given the pain and anxiety presentations of each participant, it was no surprise that this change was a welcomed relief for many. “I am learning to breathe!” one participant shared, “I used some of the techniques to just slow down and relax,” (203, personal communication, October 19, 2013). Another participant reported that through this process, “I learned that I have the ability to stop my mind from racing by focusing on breathing and calming down,” (204, personal communication, October 21, 2013). Both examples demonstrated how these participants used their breathing to decrease their stress levels and calm their minds and bodies. Another participant shared, “I don’t know if the tapes actually reduced any pain, but I believe the deep breathing helped redirect my thoughts to another place that did help me to tolerate it,” and reported, “I learned that I have not been breathing deeply. By listening to the CDs I was able to feel my ability to breathe and relax had increased,” (203, personal communication, October 19, 2013). Breathing was also correlated with an increased sense of calm for another participant, she shared: “when I wake up in the wee hours and find myself cycling, I can start to breathe and that takes me out of my head,” (205, personal communication, October 24, 2013).

Physiological improvements were reported by six participants in the form of altered experiences of pain (e.g. pain relief, increased tolerance of pain, changed perception of pain, etc.), improved sleep (e.g. falling asleep easier, increased quality of sleep, waking more refreshed, falling back to sleep if woken early, etc.), increased energy, increased comfort, and improved use of breathing.

Summary

This chapter contains a description of the findings and analysis of the data. The demographic information of the participants was detailed and the methodology was reviewed. Contextual findings were then presented to provide the reader with some background data and the three topics of investigation were expanded upon with their corresponding master themes.

Chapter 5: Conclusions and Implications

This study explored the experiences of persons with MS in order to better understand how this disease affects one's quality of life. Additionally, this study explored what role pain plays in their lives and what changes, if any, were experienced when the participants applied the therapeutic tool of self-hypnosis. This chapter begins by summarizing an interpretation of the data and then integrates the findings into prior research. Clinical implications are explored and the strengths and weaknesses of this study are discussed before suggestions for future research are made. The chapter is then completed with a conclusion of the study.

Interpretation

MS is a unique disease that affects everyone differently. The pains associated with MS, the symptoms, the triggers, the medical treatments necessary to prevent a relapse, the course of the disease, etc., were found to be different for each participant. Davis (2010) was accurate in that it truly felt as if each person had a different illness. Participants who had a longer, more advanced history with MS shared very different perspectives and experiences than those who have been more recently diagnosed. That being said, all eight participants experienced a negative impact to their quality of life by MS, whether diagnosed one year ago, or 26 years ago. The ways and degrees in which that impact has been made appeared to correspond with the amount of time that has passed since the diagnosis. Three of the eight participants emphasized that they also feel that MS has altered their life for the positive in that it has inspired them to assume a more grateful perspective, better care for their bodies, and make better life decisions (e.g. career, family, priorities, etc.). Yet I feel it important to emphasize that all three of these

participants were more recently diagnosed and are all currently mobile and independent. These three participants were also open to share that when their symptoms were intense and interfered with their daily functioning their focus would most likely lean more towards the negative.

This study revealed that the eight participants, although ranging in age, gender, symptomology, and walks of life, thematically emphasized connectivity, level of functioning, positivism, and hope as determinates for quality of life. All eight participants underscored how their ability to build and maintain connectivity to the people they value and their ability to maintain an adequate level of functioning to be self-sufficient and active in these relationships, were strong factors in defining and maintaining their quality of life. If either of these measures were compromised, their reported quality of life appeared to fall drastically. Perspective appeared to correspond with perceived quality of life as well, as participants who reported positivism and hope expressed a higher level of perceived quality, and participants who expressed negativism and hopelessness reported a much lower quality of life. This is not to suggest, however, that there is a causal relationship between positivity or negativity and the perceived quality of life, as this was not the focus of this study and proper measures were not in place to explore cause and effect relationships.

Pain was found to be a central part of most of the participants' lives and seven out of eight participants reported suffering daily physical pain. The physical, mental and emotional components of pain were each reported to have drastic impacts on these participants' lives, and the combination was reportedly debilitating for at least two. Although some reported adapting to their pain, no one reported that their pain did not

limit them and alter their lives against their preferred existence. Pain reportedly consumed and taxed the mental resources of six of the participants as it was a distraction, resulting in them painstakingly planning (e.g. planning to avoid heat, to conserve physical, mental and emotional energy, to avoid potential flares, to navigate through the physical demands of an environment, etc.), and was generally an exhausting ordeal. Some participants also described their cognitive interruption as a pain for them as it hindered their ability to interact appropriately with their environment and execute higher functioning skills. And finally, pain was described in detail to be emotionally overwhelming. Participants explained how their pain has led to dark desperation, overwhelming helplessness, fears, self-loathing, difficulty with acceptance (of self, illness, changes, etc.), isolation and loneliness, depression, anxiety, anger, and exhaustion – among others. The emotional element of pain appeared to cause more distress than the physical and mental for most.

The journals were collected after participants had administered self-hypnosis for four weeks; all but one participant submitted their journals. Six of the seven participants, according to their journals, experienced a combination of the following positive effects of hypnosis: increased quantity and quality of sleep, decreased anxiety, increased relaxation, increased energy, increased self-awareness, increased confidence, improved attitude, decreased pain, improved decision-making abilities, increased positivity, heightened awareness, gratitude, and increased control over thought patterns. One participant reported not feeling any effects of self-hypnosis. None of the participants mentioned any negative effects to hypnosis and six out of seven participants stated that they were extremely likely to use hypnosis in the future to manage their MS symptoms and to

recommend hypnosis to others with MS. After analyzing the journal entries, it appears that the use of self-hypnosis as an adjunct treatment for MS, when approaching both physiological and psychological objectives, is a beneficial and effective course of action for most.

Integration

Prior research indicated that diagnosis for MS is complicated as there is still no test or imaging procedure that can produce a unequivocal, standalone diagnosis (Kalb, 2012; National MS Society, n.d.a) and because MS is such a complicated disease to diagnose, misdiagnoses, and missed diagnoses are not unusual (Hill, 2003; National MS Society, n.d.a). The interviews with these eight participants substantiated these challenges and spoke to the negative effects that this has had on them. For instance, one participant reported twenty-four years between first diagnosis and treatment because no medical professional could confidently confirm her diagnosis but instead “waxed and waned,” (206, personal communication, August 7, 2013). Another participant who was diagnosed a year ago after finding a large lesion on his spine and then a smaller one in his brain reported that although he religiously takes his DMD daily, he is not fully certain that he trusts the diagnosis, and stated, “I don’t know...I’m not 100% on whether or not I trust the diagnosis, only because it was such a weird thing,” (207, personal communication, August 19, 2013). Another participant shared that she believes that she has been suffering the symptoms of MS for almost twenty years prior to being diagnosed (203, personal communication, August 2, 2013). Because of the emphasis placed on early diagnosis and DMD treatments, the consequences of discovering MS decades after the damage has begun in one’s body further complicates treatment and life with this

illness. The lack of clear diagnostic tools leaves people second guessing their medical providers and making life changing decisions (e.g. to take DMD treatments or not) without concrete information. This is especially daunting when we consider that studies that observed the natural course of this disease have uncovered that void of any disease-modifying treatments, over half of those diagnosed with RR will advance to a progressive type within 10 years, and 90 percent within 25 years (Hill, 2003; Kalb, 2012). Additionally, through this study, it appeared that mentally and emotionally processing and accepting such a diagnosis was further complicated by the uncertainty of the professionals and tests that indicated the diagnosis, the danger of not treating the illness, and the available courses should they agree to treatment.

Medication treatments were reportedly complex and emotionally heavy topics for almost all of the participants. Seven of the eight participants are currently on DMDs, the eighth participant recently discontinued DMDs after years of use. Research indicates that when taken long-term, DMDs reduce the frequency and severity of relapses and exacerbations and decelerate the disease; however these treatments are paired with mild to deadly side-effects (Durelli et al., 2002; MS National MS Society, 2012). Participants spoke in length about their battle with these medications. One participant shared how her current DMD has been known to cause a deadly brain disease and that it is recommended that people are not on it longer than two years; this participant has been on this medication for five years and reported:

But I'm stuck. I don't know what else to do, and the thought of getting off all meds, although a lot of people do and do okay, I can't wrap my mind around it because I'm in such a progressed state that I don't know how much more I would

have progressed had I not been on the [med], and I'm petrified to not at least be on something and look back later and go, "Oh my gosh. Why did I get off that?"

(203, personal communication, August 2, 2013)

The emotional struggle with medication that was reported by all eight participants was profound. Most participants reported feeling like medical "guinea pigs" and reportedly felt reluctant to take their medications, even those that they were so grateful for. It is a "love/hate thing," five participants expressed. Greco, Rudy, and Manzi (2004) similarly found that persons with systemic lupus erythematosus (SLE) were often found to be reluctant to add further medications (whether analgesics, opioids, or antidepressants) to their already cumbersome list of SLE medications, regardless of their need. Along similar grounds, Greco, Rudy, and Manzi's (2004) study revealed persons with SLE experienced pain, changes in social roles, fatigue, reduced productivity, depression, and unpredictability of flares that resulted in further and more complicated psychological and physiological burdens than just the illness itself. These difficulties, among others, were also observed in the eight participants in this study.

Eight out of eight participants reported frustration, anxiety, fear, and concerns surrounding pharmaceutical interventions. Donatone (2013) asserted, that "given the limitations of medication, patients are increasingly motivated to engage in non-pharmacological pain management techniques" (p. 327). I found this to be accurate as most of the participants reported that their negative and trying experiences with expensive and often dangerous medications drew them to participate in this study in hopes of having additional and safer options. Gatlin and Schulmeister (2007) contended that non-pharmacologic treatments that can effectively treat patients' pain are too often

disregarded and underutilized and that the use of these alternative methods can help persons to manage their pain by altering their pain perceptions, increasing their pain tolerance, reducing the intensity of the perceived pain, and generally increasing their adaptive behaviors. Where six of the eight participants reported using CAMs to treat their MS, none of the participants had yet tried hypnosis to manage their MS symptoms. As detailed above, six of the seven participants reported various positive changes with the therapeutic tool of hypnosis and no participant reported negative effects. Although the populations had other diseases and conditions, the findings of this study aligned with former studies in that hypnosis was found to improve psychological factors such as depression, anxiety, and increasing overall quality of life, as well as physiological improvements of diminished pain, decreased discomfort, and improved sleep (Elkins, Jensen, & Patterson, 2007; Elkins et al., 2004; Dignes et al., 1997; Gay, Philippot, & Luminet, 2002; Gholamrezaei, Ardestani, & Emami, 2006; Gonsalkorale, Houghton, & Whorwell, 2002; Peynovska et al. 2005; Spiegel & Bloom, 1983). Olson (1984) asserts that “hypnosis is perhaps our most powerful clinical intervention short of medication, however it is also the intervention most sensitive to the client’s ultimate purposes...if for some conscious or subconscious reason the client resists, hypnosis will have little or no effect” (p 414). This leads to the question of what impact the resistance (e.g. to treatments, support, helping devices, and health) that some of the participants shared having, and any resistance that transpires at a subconscious level, had on the outcomes of this study. Questions like this, however, cannot be answered in this study, if in any.

Elkins, Jensen and Patterson (2007) maintained that the particulars of frequency, mode (recording versus live session), standardized versus individualized scripts, and best

practice for self-hypnosis have not been determined and that where some persons report experiencing an immediate reduction in the severity of pain following hypnosis, others only experienced a decrease in pain after repeated practice. The participants in this study were given six prerecorded scripts to use at their preferred frequency and sequence. Each participant applied their scripts in various orders and eventually gravitated almost exclusively to scripts of their liking. The frequency of use ranged from nine to thirty sessions, with a mean of 17.25. The frequency and script selection did not appear to have any relationship with reported efficacy and changes. The one participant who reported that the recordings weren't effective did however report that he felt the mode of delivery was the problem, and that he found the in-person exercise effective, just not the impersonal prerecorded sessions.

Clinical Implications

This study indicates that chronic pain associated with MS is a multifaceted phenomenon that gravely affects more than just the physical body, but also has serious mental and emotional implications for persons as well. It is critical for not only practitioners to be aware of this powerful triad, but also for persons with MS and their supportive circles. The physical pain that people reported manifested itself in guilt, anger, frustration, diminished self-esteem, reduced quality of life, hopelessness, reduced patience for others, helplessness, and isolation, among others. Being aware of the many ways in which pain affects them will better allow persons with MS to seek and receive the guidance and support necessary to flourish, as well as help practitioners address these separate, yet related, needs of their patients.

A common frustration that was expressed by over half of the participants was that they did not feel as if their doctors [also clarified as Western medical doctors] supported and valued their decisions to employ CAMs and other lifestyle changes (e.g. diet, exercise, etc.) or even valued the non-Western medicines in general. One participant shared:

I can't say how many times I see an MS doc and it's like, "Who's your primary care doctor? Don't you see a real doctor? A naturopath is not a real doctor." It's just like, that is a real doctor! Yeah, they can't prescribe all the drugs that you can, but I don't want the drugs anyway, that's not my focus. (205, personal communication, August 7, 2013)

Some medical professionals were even reported to have advised their patients against making these changes, arguing that these changes would not be helpful. Patients need to not only feel that their belief systems are valued, but also that they can trust the authority of the doctors making life-changing decisions with and for them. When healthcare professionals discredit the use of CAMs and other lifestyle changes, it can hurt their credibility in the eyes of their patients, and perhaps more importantly risk depriving patients of valuable treatment options. According to the findings of this study, persons with MS often feel that their options are limited and that they are overwhelmingly helpless in their own bodies. The more non-pharmacologic treatment options are available to MS patients to choose from, the more empowered they may feel to advocate for their health. The participants in this study reported that most of their (Western) medical team felt like "drug-pushers". To treat a patient as a passive recipient can lead to harmful levels of disempowerment and hopelessness. Additionally there is ample

research to indicate that many CAMs, hypnosis included, are beneficial treatment options with limited risks and/or contradictions to other treatments. Persons who feel empowered naturally take more ownership over their health and lifestyle decisions and may therefore be more apt to be treatment compliant and follow through with treatment regimens.

Hypnosis is not only a tool that persons can learn and apply on their own, void of professional presence, but it is also an economically advantageous treatment.

A plethora of positive changes can be observed in this study through the reported experiences of six out of seven participants in just a four week time span and when using scripts that incorporated post-hypnotic suggestions that centered mostly around pain reduction. With this information in mind I would reason that tailored scripts that expand to other non-pain related topics would also benefit this group and their diverse needs.

Strengths and Weaknesses

This study yielded an abundance of information and positive results; however a few design weaknesses were identified. This study had a low sample size that lacked racial diversity. Diversity in races may contribute to a more well-rounded impression of how MS, pain, and self-hypnosis is more generally experienced. Additionally, a more even gender split may enhance this study. The interviews and journals took a brief snapshot of these persons' lives with MS. The interviews transpired at the onset of the study, void of established rapport. Given the findings that many of the participants are very private about having MS and are reluctant to share of their suffering with even their closest of friends, this approach to collecting this personal information may be a weakness to this study. The hypnosis recordings in this study were standardized and recorded from six regulated scripts. Yapko (2012) cautioned that scripts for hypnosis are

too standardized and oversimplify the clients' needs. He further suggested that "the use of scripts robs hypnosis of its real potency, the strength derived from the recognition and use of the individuals' unique experiences and needs," (p. 43). According to this point of view, the use of scripts could be considered a weakness to this study as well. Other weaknesses include the length of the study and the lack of long-term follow-up. The intervention phase was four weeks in this study. Given the unpredictability of the disease and frequent changes experienced by persons with all courses of MS, a longer treatment would be worthy of investigating. Additionally after treatment, long-term follow-up with participants would be useful in identifying both additional changes, as well the question if those changes are lasting.

Future Research

The following suggestions for future research are based upon the experiences of this study. Future directions for research may include hypnotic scripts that focus beyond pain analgesia and include some of the other shared thematic struggles (e.g. anxiety around the unpredictability of MS, guilt associated with illness, independence, self-identity, self-acceptance, etc.). Furthermore, a study that offers personalized treatments to address the participants' individual needs may be beneficial. A study that administered the hypnosis via prerecorded sessions and in-person sessions may shed some light on whether the efficacy of treatment is affected by the mode of delivery. Three participants in this study had a near thirty-year history with active MS. All three suffered severe pain and greatly diminished functioning (e.g. mobility, cognition, reduced independence, etc.). The two females reported grave depletion in their self-identity, hopelessness, high desperation, anger, and depression associated with the life that their MS has left them

with. The male, on the other hand, reported that his self-identity is untouched, and although physically limited he just does everything slower, and that he rarely struggles with depression or questions of “why me?” A study that explores gender differences in persons’ experiences with- and response to- advanced MS would be beneficial. Finally, multiple participants referenced the healing nature and assistance of the breathing exercises in the hypnosis scripts. Future research that focusses on MS and restricted breathing may bring forth some information that would benefit the practitioners as well as the persons with MS.

Conclusions

MS is an unpredictable and challenging disease for which there is currently no cure. Conventional treatments have significant side-effects and involve considerable risks. Even when undergoing these treatments, persons with MS are still left suffering temporary and long-term symptoms that the medications create and/or do not effectively treat. This interpretative phenomenological analysis examined the lives of eight MS participants and identified shared themes in their experiences with MS, specifically: how this disease affects their quality of life, what role pain plays in their lives, and what changes, if any, they experienced when they applied the therapeutic tool of self-hypnosis. Where most persons reported that their idea of quality of life was fluid, changing by the day – and sometimes moment, all participants reported their quality of life has been negatively affected by MS. The common thread between the participant’s measurement of quality of life included: his/her connectivity with others, level of functioning, positivism and hope. The unpredictability of the disease was addressed by all participants and reported by almost all to affect each of these four domains. Seven

participants reported feeling daily physical pain and that pain has a profoundly negative and complex impact on their lives. Pain was found to be physically tormenting, mentally consuming and emotionally inundating for these persons. After four weeks of self-hypnosis, six out of seven participants reported positive changes in their emotional regulation, intrapersonal growth, cognitive functioning, and their physiological state; the seventh reported no experienced change with hypnosis. No negative or adverse effects were reported by any of the participants. Overall this study demonstrated that the participants in this study fight a disease that affects far more than their central nervous system, but also their mental and emotional well-being as well. Self-hypnosis was found to be an effective treatment for the majority of the participants in treating some of the mental, emotional, and physical ailments of this population. With an increased understanding of the complex impact that MS has on persons, we can learn to better support, treat, and empower the people with MS. Quality of life is subjective, yet invaluable. Based upon this initial case study inquiry, it is possible that self-hypnosis could be an effective and personalized tool for meeting the multifaceted needs of this population.

Summary

This study explored the experiences of persons with MS in order to better understand how this disease affects one's quality of life. Additionally, this study explored what role pain plays in their lives and what changes, if any, were experienced when the participants applied the therapeutic tool of self-hypnosis. An interpretation of the data was presented in this chapter and the findings were then integrated into prior research. Clinical implications were explored and the strengths and weaknesses of this

study were discussed as well as recommendations for future research were made. The chapter is then completed with a conclusion of the study.

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APPENDIX A
Interview Guide

Interview Guide

Are you able to write in the journal?

How did you come to learn that you have MS?

What does it mean to you to have MS?

Has that meaning changed over time?

How do you define and measure “quality of life”?

Has your quality of life been shifted by MS? How?

How does MS affect your personal identity? How?

Does MS affect how you believe others perceive your identity?

What role does “pain” play in your life – mentally, emotionally and physically?

Can you tell me about your experiences with medication?

What role do medications play in your life?

Do you have concerns [related to this illness? These medications?]

Have you ever tried hypnosis before?

What have your previous experiences been like?

If not, do you have any reservations or concerns?

What objectives are you aiming to achieve with hypnosis?

APPENDIX B

Disclosure and Consent Form

DISCLOSURE & CONSENT FOR PARTICIPATION

ASHLEY LINN

DOCTOR OF COUNSELING PSYCHOLOGY STUDENT

at

NORTHWEST UNIVERSITY

Under the Supervision of Dr. Jacqueline Gustafson

5520 108th Avenue NE, Kirkland, WA 98033

425.822.8266

Introduction to the Research

This study was designed to better introduce researchers, practitioners, those living with Multiple Sclerosis (MS) and those without, to the thematic adversities and experiences of persons living with this challenging disease. This study is intended to bring focus to the lives affected by MS and to create a more human-focused launching point for future studies and personalized treatments. This study will introduce hypnosis as an intervention and explore how this treatment affects those with MS.

Procedures

Adult males and females who have been diagnosed with MS are invited to participate in this research study. Your involvement is entirely voluntary. Participants will be asked to sign this consent form and take part in a confidential one-on-one recorded interview of approximately one hour in length at Northwest University (or elsewhere via other arrangements). Two “orientation to hypnosis” meetings will take place, one at Northwest University in Kirkland and one on Bainbridge Island (TBD) to introduce the participants to the study and to train them in conducting self-hypnosis. All participants are encouraged to attend one of these two meetings. Should this not be possible, a video recording of this orientation will be provided to these individuals. During these meetings participants will be asked to fill out a demographics and health questionnaire. You may choose not to answer any question on this survey; your care will not be affected if you choose not to answer a question. Participants will then receive a journal and a set of CDs with 6 scripts for self-hypnosis. From this point, all participants will engage in self-hypnosis at their discretion. Where it is suggested that all participants listen to each

script multiple times, participants will elect their own frequency. All participants will be asked to record the dates and script number of each applied treatment in their provided journals. Each participant will be asked to complete four entries in these journals as well, one per week. These journals will be collected at the final meeting where each participant will be asked to complete a final survey and collect their compensation package. The locations for this final meeting will be the same as the orientation meeting in Kirkland and Bainbridge Island.

Risks or Discomforts

All participants are encouraged to follow the orders of their prescribers during their participation in this trial. This study and its provided interventions are not intended to be a substitute for their medical regimen. Medical support and advice is beyond Northwest University and Ashley Linn's scope of practice. All participants are encouraged to gain the approval of their medical provider before entering into this study.

Minimal risks are anticipated for participation in this study. For instance, it may be difficult (physically and/or psychologically) for you to allow yourself to recognize and feel your pain, an important part of a holistic mind-body exercise. Each exercise is created to walk you through these challenges of experiencing the pain and then strengthening your ability to overcome it psychologically and physically. Some experience mild dizziness after leaving a hypnotic state, this usually passes quickly and you are encouraged to maintain deep breathing and remain safely laying or sitting until it passes. Also, some feel very emotional before, during and/or after treatment; this is an important aspect of treatment and we do not endorse avoiding these responses, but

instead encourage you to recognize this as a natural release of emotions and advise you to not be concerned. All participants are encouraged to seek professional help if they have any symptoms that persist or cause them distress.

Benefits

Where benefits are speculation, we hope that you find benefit from this study with reduced symptoms of pain and discomfort, and an overall increased quality of life. This may come in many forms including, but not exclusive to: increased relaxation, increased ability to find restful sleep, an increased understanding of your unconscious mind, etc.

Confidentiality

All study records will be kept confidential and physically secure from unauthorized access. To protect your privacy, all records will be maintained under a code number, rather than by name. All written documents will be maintained according to HIPAA laws. Please note that where electronically submitted files are accepted, Northwest University and the researcher cannot guarantee their confidentiality and these should be submitted at your own discretion.

Cost/Payment

The only cost to you for participating in this study is the time you spend and travel cost to get to the meeting sites. Each participant's completion is critical to the research. This study will not succeed unless we have enough people who see it through from start to finish. Thus, we ask you to join the study only if you think that you may be able to do

that. While we hope that you will stay to the end, you have the right to withdraw at any time and for any reason and will still be fully compensated.

Compensation

All participants will be compensated with a small gift package containing gift certificates and other small mementos (minimum worth of \$100 each).

Right to Refuse or Withdraw

You are free to withdraw from the study at any time and for any reason.

Persons to Contact

If you have any questions or concerns about the study, please contact Ashley Linn, the chief researcher at hypnosis.ms@gmail.com. If, for any reason, you are not comfortable contacting her, the supervising professor is Dr. Jacqueline Gustafson, she can be reached at jacqueline.gustafson@northwestu.edu.

Researchers' Hypnosis Education and Training

Ashley Linn attained her Master's Degree in Counseling Psychology in 2006 and is in the sixth year of her Doctorate of Psychology program at Northwest University in Kirkland, Washington. She attended and completed a Hypnotherapy Training at the Wellness Institute in Issaquah, WA and a three-part hypnotherapy training seminar at Counseling for Success in Seattle, WA. Ashley had the professional assistance of certified hypnotherapists Tracy Adams and Barbara Dailey in the construction of the hypnosis

scripts used in this study. The researcher is permitted by Washington State law to practice hypnotherapy without licensure as she meets exemption criteria WAC 246-810-011, due to her status as a university student and her practicing hypnotherapy for no compensation.

Confidentiality

We will aim to always protect your right to privacy. It is important that you understand that where you are protected under the provisions of the Federal Health Insurance Portability and Accountability Act (HIPAA), some limitations to your rights to confidentiality apply; these exceptions are described below. Where your participation in this study necessitates that the researcher shares some of your provided information (e.g. your interview answers, ledgers, surveys, etc.), all identifying information will be securely maintained separate from your written and recorded documents, as to further protect your privacy. If you elect to communicate with the researcher or university via email, please be aware that email cannot be guaranteed confidential. All emails are retained in the logs of your and our internet service providers. While under normal circumstances no one looks at these logs, they are, in theory, available to be read by the system administrator(s) of the internet service provider. Any email received from you and sent to you will be electronically saved and kept in your electronic treatment file.

Exceptions to Confidentiality

The following are legal exceptions to your right to confidentiality. Please note that you will be informed prior to these being put into effect.

1. If there is reason to believe that you will harm another person, we must attempt to inform that person and warn them of your intentions. We must also contact the police and ask them to protect your intended victim.
2. If there is reason to believe that you are abusing or neglecting a child or vulnerable adult, or if you give information about someone else who is doing this, we must inform Child Protective Services within 48 hours and Adult Protective Services immediately.
3. If there is reason to believe that you are in imminent danger of harming yourself, we may legally break confidentiality and call the police or the county crisis team.
4. If you disclose the behavior of another named health or mental health care provider that suggests that this person has either (a) engaged in sexual contact with a patient, including yourself or (b) is impaired from practice in some manner by cognitive, emotional, behavioral, or health problems, then the law requires us to report this to their licensing board at the Washington Department of Health.

Record-keeping

All records will be securely maintained as outlined by HIPAA laws. This data includes, but is not limited to: consent for participation, interview transcripts, surveys, journal entries, personal data, etc.

Other Rights & Restrictions

You have the right to discontinue participation in this study at any point and will still be fully compensated. You have the right to refuse to answer any question in both written and verbal form. You have the right to ask questions about the survey and treatment at any time.

Your Responsibilities as a Participant

All participants will be interviewed one time, prior to beginning the intervention of hypnosis. All participants are required to attend or watch a recorded session of the orientation session to hypnosis prior to applying self-hypnosis. All participants will be given a journal where they will record 4 entries, once weekly, over the course of the 4 week study. These journals are to be returned to Ashley in person at the completion of the study. All participants will be asked to complete one final survey at the completion of the study. All participants are responsible to contact Ashley immediately if they are unable to maintain these responsibilities or if they are electing to drop out of the study.

INFORMED CONSENT FOR PARTICIPATION

I, _____, have read this consent form thoroughly and agree to be in this study. The procedures of this study have been explained to me and I understand them. I have been given an opportunity to ask questions and I feel that all of my questions have been answered. I understand that my confidentiality will be honored, yet also understand the limits to confidentiality as outlined by the federal law. I am at least the age of eighteen, have been advised of the scope of this study, and give my full consent to receiving hypnosis/hypnotherapy for this study and being audiotaped for this study. I understand that I am consenting to research, thus I am not guaranteed results. Hypnosis is not a replacement for medical treatment, psychological or psychiatric services, and/or counseling. I also understand that I will not be treated, prescribed for, or diagnosed of any condition. I understand that the researcher is a student of Northwest University. I know that being in this study is my choice and I may leave it at any time – however by signing this I am confirming that it is my honest intention to participate in and complete this study to the best of my ability. Should any concerns arise, I know that I may contact Ashley Linn at hypnosis.ms@gmail.com. I have received this disclosure in duplicate form, releasing one copy to this study and retaining the other for my personal records.

Participant's Signature: _____

Participant's Printed Name: _____

Researcher's Signature: _____

Date: _____

INFORMED CONSENT FOR PARTICIPATION**[Duplicate – Participant’s Copy]**

I, _____, have read this consent form thoroughly and agree to be in this study. The procedures of this study have been explained to me and I understand them. I have been given an opportunity to ask questions and I feel that all of my questions have been answered. I understand that my confidentiality will be honored, yet also understand the limits to confidentiality as outlined by the federal law. I am at least the age of eighteen, have been advised of the scope of this study, and give my full consent to receiving hypnosis/hypnotherapy for this study and being audiotaped for this study. I understand that I am consenting to research, thus I am not guaranteed results. Hypnosis is not a replacement for medical treatment, psychological or psychiatric services, and/or counseling. I also understand that I will not be treated, prescribed for, or diagnosed of any condition. I understand that the researcher is a student of Northwest University. I know that being in this study is my choice and I may leave it at any time – however by signing this I am confirming that it is my honest intention to participate in and complete this study to the best of my ability. Should any concerns arise, I know that I may contact Ashley Linn at hypnosis.ms@gmail.com. I have received this disclosure in duplicate form, releasing one copy to this study and retaining the other for my personal records.

Participant’s Signature: _____

Participant’s Printed Name: _____

Researcher’s Signature: _____

Date: _____

APPENDIX C

Demographics Questionnaire

DEMOGRAPHIC INFORMATION

Participant Name: _____ DOB: _____

Gender (check one): Female MalePlease select the race(s) that best describe you. (*Check all that apply*) Asian

Please specify: _____

 African American/Black Caucasian/White Hispanic, Latino, or Spanish

Please specify: _____

 Middle Eastern

Please specify: _____

 Native American or First Nations

Please specify: _____

 Pacific Islander

Please specify: _____

 Other

Please specify: _____

What is your highest level of education? (*Check all that apply*) High School Technical Training College (years) 1 2 3 4 5+ Graduate School (*circle one*) Other _____

Occupation: _____

What year were you first diagnosed with MS? _____

Which disease modifying treatment do you currently take?

 Avonex® Betaseron® Copaxone® Extavia® Gilenya™ Novantrone® Rebif® Tysabri® Other _____ Not Applicable – I don't take any medication

How long have you been self-administering this disease-modifying product for?

What side effects, if any, do you still experience?

Please indicate what, if any, substances you have used to treat your MS (marijuana, alcohol, etc.). *(Again, this is merely for demographic information, this is entirely confidential!)*

- Not Applicable – no substances used.
- I am not comfortable answering.

Please indicate what, if any, other alternate treatments you currently have used to treat your MS (yoga, acupuncture, Reiki, massage, chiropractor, vitamins, etc.).

- Not Applicable

What disease course is your MS currently classified in?

- Relapse-Remitting (RR) Primary-Progressive (PP) Secondary-Progressive (SP)
 Progressive-Relapsing (PR) Benign MS Other:_____ I don't know

APPENDIX D

JOURNAL

APPENDIX E

Final Survey

