Mindfulness Based Stress Reduction in Couples Facing Multiple Sclerosis: Impact on Self Reported Anxiety and Uncertainty

by

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Abstract

MINDFULNESS BASED STRESS REDUCTION
FOR COUPLES FACING MULTIPLE SCLEROSIS:
IMPACT ON SELF REPORTED ANXIETY AND UNCERTAINTY

by

Vered Miriam Hankin

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Nearly 2.5 million people in the world have MS (The Multiple Sclerosis International Federation, 2007). MS is an auto-immune disorder, involving the white matter of the brain and spinal cord. Symptoms vary and can come and go, appear in any combination, and may be mild, moderate, or severe. The prognosis and time-course of the disease is often unclear. The disease can create a great deal of uncertainty, particularly in newly diagnosed patients (Noseworthy et al., 2000). Approximately 50% of patients and partners showed significant levels of either anxiety or distress (Pakenham, 1998). Additionally, patients who reported their spouses to be more encouraging have been shown to be significantly less depressed (Schwartz & Kraft, 1996). Thus, couples "react to disease as a unit" (Pakenham, 1998, p. 269). Rolland (1985) concurs that "the well spouse faces many of the same dilemmas" (p. 240).

Mindfulness Based Stress Reduction (MBSR), an eight-week course incorporating yoga, meditation, and mind-body awareness, is a skills training technique which has successfully combated many physical and emotional ailments. This study

evaluated the effect of MBSR on the uncertainty and resulting anxiety of each partner, as well as on the relationship. Twenty-five couples were recruited into two MBSR groups, with one couple partner diagnosed with Relapse-Remitting MS. Quantitative self report measures assess physical symptoms, anxiety, relationship satisfaction, perceived illness uncertainty, and intolerance of uncertainty. Data was collected before and immediately after the intervention. Results indicated a positive change in patient and partners levels of anxiety and uncertainty as well as in their relationship satisfaction. Results from this study contribute to the field of available interventions for couples dealing with chronic illness, and specifically MS. Additionally, it illuminates an important and yet undiscovered element of mindfulness meditation as a tool in coping with family illness.

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CHAPTER ONE

Introduction

An estimated 400,000 Americans have Multiple Sclerosis (MS). Most are diagnosed between the ages of 20 and 50, and about two-thirds are women (National MS Society). MS is an auto-immune disorder involving the white matter of the brain and spinal cord. Symptoms may include muscle tingling or tightness, loss of balance, sexual dysfunction, blurred vision, slurred speech, difficulty in memory and concentration, and/or paralysis; these may come and go, appear in any combination, and be mild, moderate, or severe, with the most severe variants leading to wheel chair dependence, and a shortened life span. There are three types of MS: relapsing/remitting, progressive, and a more rare form that comes on suddenly and severely. Generally, an individual is diagnosed after several months to several years of unexplained symptoms; the prognosis and time-course of the disease is often unclear upon diagnosis. The disease's unpredictability in symptoms and severity can create a great deal of uncertainty, particularly in newly diagnosed patients (Noseworthy et al., 2000).

Examining newly diagnosed patients with an average of eight months after MS diagnosis, approximately 50% of patients and partners showed significant levels of either anxiety or distress (Pakenham, 1998). In general, patients and partners did not differ in levels of anxiety (Northouse, Dorris, & Charron-Moore, 1995), but patients did demonstrate a greater tendency to avoid MS-related feelings (Pakenham, 1998). Additionally, patients who reported their spouses to be more encouraging have been shown to be significantly less depressed (Schwartz & Kraft, 1996). Thus, couples "react to disease as a unit" (Pakenham, 1998, p. 269). Schwartz & Kraft thus suggest the

importance of targeting spouses, in addition to patients, in interventions. As Rolland (1985) concludes,

> [f]acing and accepting loss should not be limited to the ill partner. It has never been limited to one partner and never will be. Because of his or her disability, the immediacy of loss may be heightened for the ill partner, but the well spouse faces many of the same dilemmas (p. 240).

Pakenham highlights this same perspective stating that findings suggest that "psychological interventions for couples with MS should include both carer and receiver" (1998, p. 276). Nevertheless, previous interventions have been almost exclusively focused on the ill person, without attending to his/her partner. He also adds that

> [r]esearchers in other illness areas have suggested that conjoint therapy is a more effective treatment approach than supporting the care receiver or the caregiver separately. Evidence is accumulating suggesting that involvement with family caregivers of chronic pain care receivers in treatment improves the quality of relationships, reduces psychological distress, and reduces chronic pain-related behaviors (Pakenham 1998, p. 276).

Finally, he concludes that "I could find no published reports of interventions designed to assist MS care receiver-carer dyads" (p. 276). Specifically Pakenham suggests implementation of "skills training techniques… and active cognitive or behavioral strategies" (p. 276). Other researchers add that an essential intervening element of multiple family groups -- one form of intervention that has been used with a wide variety of medical and psychiatric illnesses -- is "the ability to 'step back' from oneself… that creates the opportunity for families to consider a new and better balance between illness versus non-illness needs and priorities in their lives" (Steinglass, 1998, pp. 67-68).

One such skills training technique which has been successfully used to combat both physical and emotional illness is Mindfulness Based Stress Reduction (MBSR).

MBSR is an eight-week course that includes gentle yoga, meditation, and body awareness, with an emphasis on the concept of "mindfulness," an awareness of the present moment. This intervention incorporates behavioral and cognitive exercises with an analytic "ability to step back (Steinglass, 1998, see above)." Each session covers particular exercises and includes different forms of meditation practice, such as cultivating body awareness during stillness and movement, and emphasizing an ability to incorporate this awareness during stressful emotional and/or physical life situations.

Previous research has shown that MBSR alleviates chronic pain (Kabat-Zinn et al, 1986, 1985), increases immunity (Davidson et al, 2003), increases quality of life (Greeson 2001) and decreases anxiety (Kabat-Zinn et al, 1997). Specific diseases that have been shown to have benefited from MBSR interventions include psoriasis (Kabat-Zinn et al, 1998), prostate (Saxe et al 2001) and breast cancer (Carlson et al, 2003), fibromyalgia (Kaplan et al, 1993), and heart disease (Tacon et al, 2003). Additionally, a form of MBSR, Mindfulness Based Cognitive Therapy (MBCT) has targeted clinical depression, and has been found to significantly reduce relapse frequency (Teasdale et al, 2000). Further, a successful pilot study targeting MS patients, utilizing mindfulness movement and body scan meditation, showed significant physical improvement, including improvement in balance and pain reduction when compared to the control group (Miller et al, 1995). Nevertheless, only one study of MBSR and illness included significant others (Kabat-Zinn et al, 1998). However, this study included partners only in order to increase dietary compliance, and thus did not address the impact of involving both members of the couple in an MBSR intervention. In general, the discussion and results of this study did not attend to the partners at all, but only to the ill subjects.

This study explored the effect of an MBSR intervention on couples in which one of the couple partners had been diagnosed with MS. Specifically, I examined the effects of MBSR on the uncertainty and resulting anxiety of each partner, as well as on the couple as a whole. I utilized quantitative self report measures to assess the physical symptoms of the MS partners, as well as the psychological symptoms of both couple partners; an additional measure evaluated relationship change. Two measures specifically related to the effect of uncertainty were utilized, with one scale measuring one's tolerance of uncertainty, and another examining one's level of uncertainty related to one's or one's partner's illness.

Since MBSR mainly focuses on building the skills of being able to focus on the provide moment with awareness, and in limiting distraction, the hypothesis was that an intensive MBSR intervention with couples would lower couples' anxiety and increase their tolerance of uncertainty. It was presumed that as the anxiety was alleviated, patients and caretakers would be better able to attend to their own thoughts and feelings, and would thus be better able to be present in the moment, rather than caught up in the anxiety of an unknown future. Further, engaging couples in a systemic intervention would allow them to focus on a project that they were going through together, rather than the illness that, although they faced "as a unit," is a very different course for each of them. Finally, I hypothesized that by having the couples undergo the intervention together, their relationship would improve, as would their ability to face the illness "as a unit."

CHAPTER TWO

Literature Review

Introduction

As mentioned in the statement of purpose, I examined the degree of anxiety related to uncertainty in couples in which one couple member had a relapse-remitting diagnosis of multiple sclerosis (MS). I offered 25 couples an eight-week mindfulness based stress reduction (MBSR) course. Couples then responded to six quantitative measures to ascertain the effect of MBSR on their level of anxiety, uncertainty, relationship, and physical symptoms. The following literature review explores previous research and theory related to this project. First, the reader will find a summary of research on couples and families facing chronic illness. This literature serves as background information for my project, as well as provides clinical suggestions pertaining to the intervention that I used with the couples. Secondly, the reader will find a summary of previous literature pertaining to MS, specifically focusing on the role of uncertainty in MS, and on the effect on and role of couples facing MS. Next, the reader will find a summary of previous research on MBSR. Here, findings are cited indicating physical and psychological effects of MBSR. Finally, the reader will find a summary of studies that utilized mindfulness based interventions with MS populations.

Chronic Illness and Families

The Chronically Ill Patient: Listening to the "Depth"

When referring to the chronically ill patient, Frank (1998) refers to the patient as "deeply" ill, a term he reserves for a patient to define for him or herself. "Deep illness," he explains, is an illness that is "always there," with the person believing it "always will

be there" (Frank, 1998, p. 197). Frank encourages professionals to engage in "empathic witnessing… of the patient's and family's stories of the illness" (Kleinman, 1988, p. 10). Rachel Naomi Remen concurs, noting that by holding the space for her patients, she

> [o]pens up opportunities for people to be listened, to, and heard, and validated. They're not stuck anymore. If you ask, 'How does that happen?' I have to say I'm not sure – but it does, and I trust that. I think the greatest thing you can ever give someone else is your attention – not with judgment, but just listening (quoted in Moyers, 1994).

In the formulation of the narrative of one's illness, Frank discusses three basic narrative types: the restitution story, the chaos story, and the quest story. The restitution story, according to Frank, is the culturally preferred story in North America, and tells of "getting sick, suffering, being treated and through treatment being restored to health" (Frank, 1998, p. 200). This narrative represents "the triumphant optimism of medical science" (p. 201). The restitution story focuses on the treatment itself, on what is being has been done, is being done and will be done to restore the patient to health; however, upon closer listening, one might notice that the subjectivity of the ill person is virtually invisible in the stories, having been displaced by others. The second type of story, the chaos story, lies diametrically opposed to the restitution story: "Here is deepest illness: disability can only increase, pain will never remit, physicians are either unable to understand what is wrong or unable to treat it successfully" (Frank,1998, p. 201). This type of story is disorderly, and is thus unable to render the narrative ordering which requires a beginning, middle and end; instead the story "trails off in a formless sequence…" (Frank, 1998, p. 202). Chaos narratives are difficult to listen to, for their very challenge of "deep health" (Frank, 1998, p. 202). He explains that while it may be overwhelming for the listener to take in the narrative without *doing* something, this is

exactly what is needed. Indeed, it is this very holding that leads to wisdom, as in the Job story that he uses an example, where “the measure of his wisdom is his new capacity for silence” (Frank, 1998, p. 203). The third type, as delineated by Frank, is the Quest Story. This type of story arises with the acceptance of one’s illness. In it, “Illness is lived as a quest: as a condition from which something can be learned (though not in a didactic sense), and this learning can be passed on to others” (Frank, 1998, p. 203). This acceptance does not in any way imply that the ill person is happy to have the disease, although s/he may be grateful for the lessons learned through the journey of the illness.

Chronic Illness: A Family Perspective

In *Families, Illness and Disability* (1994a), Rolland opens with a clinical vignette in which Sally, a young married woman with two small children, successfully enters remission, winning her four-year battle with cancer. It is as it this point, Rolland explains, the medical version of the story usually ends. However, in this scenario, Sally’s husband soon begins drinking and becoming verbally abusive. Her children develop behavioral problems at home and at school. Ultimately, Sally and her husband engage in a bitter, expensive divorce and custody battle. Such a vignette, not at all uncommon, illustrates a family systems perspective of the medical idiom: “the treatment was successful, but the patient died (in Rolland, 1994a, p. 1).” For, although in this case, the patient’s disease has been beaten, ultimately, the family system did not survive the course of the illness.

The tendency of the medical model to treat chronic illness as if it affected the individual alone, outside of a unit, can lead to dangerous consequences, as illustrated in the above vignette. As Rolland notes,

> Facing and accepting loss should not be limited to the ill partner. It has never been limited to one partner and never will be. Because of his or her disability, the

> immediacy of loss may be heightened for the ill partner, but the well spouse faces many of the same dilemmas (Rolland, 1994a, p. 290).

By ignoring the effect of illness on the well partner or spouse, the risk for the family unit "to die" is much higher, for several reasons. First, the balance of power within the relationship can become skewed. Secondly, the relationship may be in danger of becoming completely identified with the chronic disorder, leaving little balance for much else, and endangering the relationship as the disease condition shifts (even when a person recovers from the illness, as above):

> If the illness-framing event in a couple's relationship is defined strictly as 'my disorder and my problem,' it places the illness within the individual. This increases the risks of skew, enabling the affected partner to exert power and control through the role of sick person…. Couples are more empowered when they can view their predicament in a balanced way as a relationship issue shared by both (Rolland, 1994a, p. 241).

This can be especially problematic in severe chronic cases, such as multiple sclerosis:

> The risk is even greater in conditions that are permanently disabling, progressive, or require continuous care, such as chronic pain syndromes, multiple sclerosis, or a spinal cord injury. In these situations the disorder is an ever present, demanding continual practical and emotional energy from a couple (Rolland, 1994a, p. 242).

> Families have long been ignored in the medical model of chronic illness.

However, there are various ways that family role has been addressed in clinical research (Steinglass and Horan, 1988). The first perspective regards families as a resource, the primary source of social support, and that which helps determine treatment success and compliance. A second perspective views the family as a potential liability, contributing to disease onset, or as encouraging poor compliance. A third perspective evaluates the impact of illness on the family. Finally, a fourth perspective involves the mutual

interaction between family behavior and the characteristics of the illness, and can be a positive or negative view.

Rolland (1984, 1994a) explains that it is not enough to know that families have an important role within the illness process; it is important to understand the delicate balance between the interaction of the time phase of an illness, the illness type, and the family or partner strengths and weaknesses. Just as theorists have uncovered the importance of "goodness of fit" between a parent and a child (Thomas & Chess, 1977, pp. 15-16), so too is it important to understand the "goodness of fit" within the realm of chronic illness and the family. In order to understand this balance, Rolland categorizes illnesses and their time phases. He groups illness typology by distinguishing between them in the following ways: a. onset (acute vs. gradual), b. course (progressive, constant, or relapsing), c. outcome (non-fatal, shortened life-span or leading to sudden or early death), and d. incapacitation. Rolland then combines these categories into a grid, creating 32 typologies of illness. On this grid, multiple sclerosis is an incapacitating illness that can be either relapsing or progressive, with a gradual onset, and may be fatal or lead to a shortened life span. However, it is also important to note the time phase of the illness, be it crisis phase (pre-diagnosis or immediately after initial diagnosis), chronic phase or terminal phase. When treating families, it can be helpful to sketch out the illness and time phase on a grid, in order to best ascertain the mode of treatment.

These factors, in conglomeration with the family type, can help the clinician ascertain if the family is coping in an adaptive way. For example, as Rolland notes, during a crisis phase, it can be particularly important for a family to pull together, and this may be especially simple for a family or couple who is already enmeshed; however,

in the chronic phase such a scenario could be “stifling,” and it may be very difficult for the same enmeshed family to separate and allow for fluidity and transformation as the illness shifts (Rolland, 1984, p. 255). Rolland also notes that “[m]aladaptive patterns of coping are most likely to start in the crisis phase” (Rolland 1984, p. 258), stressing that “[t]o maximize prevention, initial clinical intervention should be targeted on the crisis phase of a chronic illness. This is especially true for acute onset, incapacitating types of illness, which present the greatest strain to a family.” Relapse Remitting Multiple Sclerosis, can originally hit acutely, and can come and go at anytime, leading many family units to need to be constantly ready to re-encounter a relapse, even in times of remission. Thus, while some would categorize MS as a gradual onset illness, it’s unpredictability may lead to similar stresses as other acute onset illnesses.

Multiple Family Groups in Chronic Illness: History and Clinical Implications

Steinglass concurs that families “are often either completely ignored or at best tolerated in medical settings” (Steinglass, 1988, p. 55), even though there is widespread evidence that the family has a “profound impact” on the clinical course of medical illness (Campbell, 1986; Fisher et al., 1992); this is in addition to the notion that families themselves are strongly affected by a patient’s medical illness, as noted above (Rolland, 1984, 1994a). One example showing the crucial effect family can have on an ill individual is a study that showed three family factors that could predict early death at 100% (Reiss et al., 1986). Patients’ medical status, however, showed 0% predictive accuracy (Reiss et al., 1986). Surprisingly, family qualities that predicted early death are family members who: a) are less coordinated in their problem solving styles, b) have more meaningful contact across generations, and 3) exhibit higher levels of

accomplishment. As a result of these findings, multiple family groups (MFGs) arose in order to further explore families' role in illness and recovery.

Steinglass (1998) implemented a series of multiple family groups (MFGs) for a number of medical conditions, including renal disease, diabetes, cancer, autoimmune diseases, neurological disabilities, and chronic pain symptoms. One of the main purposes of MFGs was to help families restructure around the illness demands, without falling prey to patterns that may not be adaptive. MFGs can help allow families to see when initial effort crisis stage efforts may no longer be adaptive, thus helping the family who struggles with illness chronicity find a better balance in their lives. Steinglass (1998) reports that providing a structure for the group was important. He also found that gearing the group to families with patients of different diseases was important, so that families and patients could focus on their commonalities as people, rather than on the specifics of their disease.

Examining data from the MFGs, Steinglass found that dropout rates were extremely low, despite families' initial misgivings about the large time commitment expected of them. Of the 25 families who participated in his eight session model, 23 completed the full eight sessions. Second, comparisons of pre and post group psychosocial functioning of MFG participants, through the Psychosocial Adjustment to Illness Scale, showed that non-patient family members experienced significant improvements in their work, family life and general social functioning. Overall, the MFGs were helpful in the following: a. establishing a community of families with shared experiences, b. the strength based model focus of the groups, c. allowing for multiple perspectives, and d. the "ability to 'step back' from oneself" and to take "an observational

stance" (Steinglass, 1998, pp. 67-68). This latter point is especially relevant to mindfulness interventions, as defined below.

Chronic Illness and Couples

Although many unmarried couples live together, over 90% of American adults marry at some point, with most American families organized around the married couple (U.S. Bureau of the Census, 1989, in Coyne & Fiske, 1992). Since married couples live longer and have fewer children than in the past, with children eventually leaving for college and careers, the spouse or partner is often the primary caregiver, as well as the primary person affected by his or her partner's illness. Coyne & Smith (1991) note that couples facing chronic illness find themselves battling with three "potentially competing functions: managing one's own distress (emotion-focused), attending to various instrumental tasks (problem-focused), and grappling with each other's presence and emotional needs (relationship-focused)" (p. 132). These foci can contradict each other, however. A Michigan Family Health Study provides an example of such a contradiction (Coyne & Smith, 1991). When wives made concessions to their ill husbands, the wives exhibited a higher level of distress while the husbands experienced greater self-efficacy.

Before generalizing from this study, however, it is important to note there are gender differences in caretakers and patients. For example, wives are more likely to assume more of the housework if their husband is sick, whereas men are more likely to hire a housekeeper (Zarit et al., 1986). Additionally, women are more likely than men to base their well-being on their marriage, and may have more of a need to address marital difficulties (Gottman, 1991). Finally, research shows that in traditional families, the illness of the wife or mother has the greatest possibility for negative impact on a family

(Litman, 1974). On the other hand, men, who may have been socialized that vulnerability and nurture is only OK when they are sick, may have ambivalent feelings about the illness (Rolland, 1994b). Since a majority of patients suffering from MS are women (National MS Society website, 2008), these gender differences are important to note. Additionally, since most people are diagnosed with MS as young adults (between 20 and 40) it is important to note that younger couples may experience a higher level of distress around chronic illness than their older counterparts, most likely because they perceive themselves to be "off schedule" (Coyne & Smith, 1991). Further, for younger couples, such a diagnosis may cause major shifts in long term and family planning (Neugarten & Hagestad, 1976).

In "In Sickness and in Health: The Impact of Illness on Couples' Relationships," Rolland (1994b) delineates several psychological issues specific to couples facing illness. Many couples facing loss, including "ambiguous" (Boss, 2000) and "anticipatory loss" (Rando, 2000), may react by either distancing themselves from each other or becoming fused. Couples who are able to face these challenges "and use that consciousness in an empowering manner to live more fully" adapt best and experience least constraint on their relationship (Rolland, 1994b, p. 329). Thus, it seems that couples who are able to transform their story into a "quest story," as noted above (Frank, 1998), seem to cope best. This is best accomplished through the identification of difficult feelings, as well as through the establishment of "clear illness boundaries," and "rebalancing relationship skews" (Rolland, 1994b, p. 329).

Rolland suggests establishing illness boundaries by keeping the illness "in its place" (Rolland, 1994b, p. 332). He suggests that the couple delineate specific times in

which they do not discuss the illness, and instead devote time to self-care and other activities; he also recommends reserving an area of the home, such as the bedroom, that would remain free of discussions related to the illness. Rolland (1994b) also cautions couples from inadvertently creating illness-related "skews." As he notes, a powerful shift occurs within a couple when one member becomes sick: the shift from equal partners to patient-caregiver. This immediate "physical skew" needs to be acknowledged by both partners (p. 336); however, each couple member must affirm the need to take care of him/herself as well. In this way, couple members can acknowledge their different needs, creating "separateness" within the "we-ness" (p. 336). Further, if the illness is defined solely as the patient's "problem," the relationship will automatically be skewed (p. 337).

Part of accepting the diagnosis includes the couples' acceptance that their relationship as a whole may now appear to be very different from what they had originally anticipated. Rather than assuming that all hope is lost since their relationship is now different, it is important for couples to recreate their relationship, while acknowledging the parts of the relationship that are still intact. Further, Rolland recommends that the couple develop "new shared interests" and activities (p. 338). Certainly, many couples, including those with an MS partner, may find their sexual intimacy affected by the disease. It is important for couples to communicate openly about their feelings regarding sexual intimacy, as well as their limitations and preferences (Schover & Jensen, 1988). Additionally, couples may be encouraged to redefine intimacy and nurturance more broadly, perhaps to include affection, caring, and participating in shared interests. Rolland recommends support groups that are specifically geared towards couples, though often they are "not offered explicitly for couples" (p. 344). For younger

couples, he further suggests networking with other couples who are in a similar developmental stage, though he asserts that support groups geared towards developmental lifecycle are “rare” (Rolland, 1994b, p. 344).

Multiple Sclerosis

Multiple Sclerosis: An Overview

An estimated 400,000 Americans have Multiple Sclerosis (MS) (National MS Society website, 2008). Most are diagnosed between the ages of 20 and 50, and about two-thirds are women. MS is an auto-immune disorder, involving the white matter of the brain and spinal chord. Symptoms may include muscle tingling or tightness, loss of balance, sexual dysfunction, blurred vision, slurred speech, difficulty in memory and concentration, and/or paralysis; these may come and go, appear in any combination, and be mild, moderate, or severe, with the most severe variants leading to wheel chair dependence, and a shortened life span. There are three types of MS: relapsing/remitting, progressive, and a more rare form that comes on suddenly and severely. Generally, an individual is diagnosed after several months to several years of unexplained symptoms; the prognosis and time-course of the disease is often unclear upon diagnosis. The disease’s unpredictability in symptoms and severity can create a great deal of uncertainty, particularly in newly diagnosed patients (Noseworthy et al., 2000).

Uncertainty in Multiple Sclerosis

Generally, uncertainty in illness evolves out of several factors, including ambiguity of diagnosis, changes in relationships, lack of information relating to one’s prognosis, and illness unpredictability (Mishel & Braden, 1988). Whereas Cohen (1993) claims that uncertainty can have both positive and negative elements, Wineman et al.

(1990, 1994, 1996) found that for patients with MS, who experience uncertainty "as part of the essence of life" (Wineman et al., 1996, p. 58), high degrees of uncertainty lead to a more negative sense of emotional well being (Wineman et al., 1990), greater mood disturbance (Wineman et al., 1994), and higher depression with a lower sense of meaningfulness (Wineman et al., 1990).

In Wineman et al.'s study of the effect of illness uncertainty on MS patients participating in a double-blind clinical trial, Wineman et al. (1996) tested 59 MS patients, utilizing the Mishel Uncertainty in Illness Scale, along with Jalowiec's Coping Scale, and the Kurtzke Expanded Disability Scale. They found that level of education was significantly related to degree of uncertainty. Thus, controlling for level of education, as well as for level of ambulation, they found that illness uncertainty was the only variable that uniquely negatively affected participants' mood. Ultimately, Wineman et al. (1996) suggest interventions that target MS patient stress and uncertainty, especially "stress reduction techniques such as relaxation and imagery," as well as the mobilization of "social supports" (Wineman et al., 1996, p.59).

In a study of the relationship between uncertainty, illness intrusiveness and psychological distress in patients suffering from multiple sclerosis, Mullins et al. (2001) tested 78 MS patients of varying age (M= 46.3 years) and disease severity. They found that illness intrusiveness and illness uncertainty were each positively related to psychological distress, with higher measures of intrusiveness and uncertainty leading to higher psychological distress. Further, each of these variables uniquely correlated with high psychological distress, with neither one mediating or moderating the other. These variables' effect on distress held true even when researchers controlled for illness

severity, leading to the conclusion that these two factors “were more salient predictors of psychological adjustment than were objectively measured indices of illness severity” (Mullins et al., 2001, p. 148). This has important clinical implications, for “[g]iven that objective measures of illness severity are often used to guide treatment decisions, care providers may inadvertently fail to address those individuals for whom the impact of the illness may be most psychologically profound” (Mullins et al., 2001, p. 148). Based on their conclusions, the authors make several suggestions for interventions. Specifically, they suggest that future interventions focus on “enhancement of valued life activities and amelioration of uncertainty” in order to lessen psychological distress in individuals with MS (Mullins et al., 2001, p. 149).

In 2004, McNulty et al. studied the role of uncertainty and spiritual well being on psychosocial adaptation in patients suffering from MS. Based on previous research suggesting that spirituality and religion may abate the social maladjustment caused by uncertainty (Brooks & Matson, 1982; Crigger, 1996), McNulty et al. questioned whether spiritual well-being could serve as a mediator and/or moderator between uncertainty and adaptation. Results of the study show that both uncertainty and spiritual well-being (existential and religious) uniquely affected psychosocial adjustment, as well as psychological distress, with higher levels of uncertainty and lower levels of spiritual well-being negatively affecting psychosocial adjustment. These findings held true even when controlling for disability and social variables. Both aspects of spiritual well being, religious and existential, were also found to be a mediator between uncertainty and psychosocial adaptation, though there was no interactive effect found between spiritual well being and uncertainty. The one exception in this was that those who reported low

emotional well being and increased levels of uncertainty did display higher levels of psychosocial adjustment. This, the authors hypothesize, may be due to a higher level of denial and avoidance, thus resulting in amplified self-reports. Researchers conclude that since both uncertainty and spiritual well being affect MS patients, interventions should address both components.

Multiple Sclerosis and Couples

Dyadic Coping

Couples tend to "react to disease as a unit" (Pakenham, 1998, p. 269). Indeed, in a study on breast cancer, Northouse et al. found that there is a strong correlation between stress levels of patients and partners (Northouse et al., 1995). Since couples' coping styles shape each other's adjustment, Manne and Zautra (1989) examined couples' dyadic coping process in order to ascertain the proper intervention. Past research has distinguished between emotional-focused coping (with the goal of reducing emotional distress associated with the problem situation) and problem-focused coping (with the goal of changing or fixing the source of stress). Manne and Zatura (1989) found that similar emotional-focused coping strategies and dissimilar problem-focused coping strategies are most beneficial for couples. This finding has been true for couples dealing with cancer (Revenson 1994, Barbarin et al., 1985).

Pakenham (1998) decided to test whether coping strategies work similarly for couples battling MS. His findings replicate previous research: for MS patients, dissimilar problem-focused coping is adaptive both in collective couple depression and in individual patient and partner adjustment. Additionally, Pakenham (1998) found that higher mean levels of couple problem-focused coping were related to lower levels of collective

distress, while higher mean levels of couple emotion-focused coping were related to higher levels of global distress. Pakenham (1998) also hypothesized, based on past research on other forms of illness (Pakenham et al., 1995), that MS patients would report lower levels of adjustment than their partners. This prediction was also supported, with patients specifically scoring lower than their partners in the dimensions of somatization, obsessive-compulsion, depression, and phobic anxiety. Pakenham thus concludes that, as in many other chronic illnesses, MS patients also exhibit higher levels of distress than their caretakers. These findings thus distinguish MS patients and partners from couples facing breast cancer, who have been found to exhibit similar levels of stress (Northouse et al., 1995). .

There are, however, areas of similarity for MS patients and partners suffering from psychological distress (Pakenham, 1998); these include the dimensions of depression, interpersonal-sensitivity, and hostility. Since the latter two are interpersonal interactions, it makes sense that couples would exhibit similar levels of distress in these dimensions. Pakenham's conclusions are important to consider for this research project. He concludes that "Regarding practice implications, findings suggest that psychological interventions for couples with MS should include both carer and care receiver" (Pakenham, 1998, p. 276). He also adds that

> Researchers in other illness areas have suggested that conjoint therapy is a more effective treatment approach than supporting the care receiver or the caregiver separately. Evidence is accumulating suggesting that involvement of family caregivers of chronic pain care receivers in treatment improves the quality of relationships, reduces psychological distress, and reduces chronic pain-related behaviors (Pakenham, 1998, p. 276).

Finally, he concludes that “I could find no published reports of interventions designed to assist MS care receiver –carer dyads” (Pakenham, 1998, p. 276). Specifically Pakenham suggests “skills training techniques” “and active cognitive or behavioral strategies” (p. 276).

Spouse Support

Schwartz and Kraft (1999) decided to examine the impact of perceptions of spousal support on MS patients’ psychological and physical well being. Results indicated that patients’ perceptions of their spouses’ reaction to them were significantly correlated with their own perceived levels of disability. Patients who perceived spouses to be more “solicitous” in reaction to their disability exhibited a higher physical disability (Schwartz & Kraft, 1999, p. 526). The authors provide a couple of interpretations to this result. First, it is possible that patients who have greater physical disability require greater attention and assistance from their partners. Further, spouses can also be affected by the greater physical disability of these patients and thus engage in more solicitous responses. A second possibility, however, is that solicitous spouse responses may inadvertently encourage disability, and discourage a patient’s well behaviors, despite good intentions to the contrary. This interpretation is consistent with past literature related to disability behaviors in couples (Romano et al., 1992, Flor et al., 1989, Fordyce et al., 1973).

Yet another of Schwartz and Kraft’s (1999) findings is that patients who rated their spouses as exhibiting more negative reactions to their disability exhibited poorer overall mental health, and larger numbers of symptoms related to depression. Conversely, patients who reported their spouses to be more supportive were significantly less depressed. However, it is also important to note the possibility that patients who exhibit a

higher score of depression may also interpret their spouses' reactions to them as negative and unsupportive, a point the authors fail to consider. As to the role of family environment on functioning, there was no significant effect on patient physical functioning. However, mental functioning was significantly affected by family environment. Specifically, highly controlling families were correlated with low physical functioning, whereas families characterized by greater independence and self-sufficiency were associated with patients who exhibited better mental health and less perceived disability. As to treatment implications, the authors stress the importance of spousal training, particularly in reinforcing the patient's well behaviors. As they note, "marital and family processes may be related to long-term treatment success," and they thus recommend further research, as well as increased interventions, in this realm (Schwartz & Kraft, 2004, p. 529).

Multiple Sclerosis and Uncertainty

Uncertainty and Optimism

In 2000, Gold-Spink et al. decided to explore the correlation between depression, optimism and uncertainty in MS patients. Results showed that MS patients exhibited a significant positive correlation between depression and sense of uncertainty, as well as a significant negative correlation between optimism and sense of uncertainty. In addition, partners' distress regarding uncertainty was also significantly correlated with patients' levels of depression and optimism, as were the degree of optimism and distress regarding uncertainty in patients and partners. Finally, a near significant trend appeared to link level of patient functioning with level of marital satisfaction as reported by partners. It is important to note that despite previous research reports showing divorce levels to be

twice as high in couples with an MS partner (Brooks and Matson, 1987), as well as studies showing general marital dissatisfaction in relationships in which a spouse exhibits chronic health difficulties (Burman & Margolin, 1992), the majority of participants in this study reported high marital satisfaction. However, this could be due to the selection of the study.

Uncertainty Regarding Wheelchair Expectancy

Janssens et al. (2003a) attempted to evaluate couples' interpretations of MS symptoms, specifically focusing on couples' uncertainty regarding future wheelchair dependency. Actual risks of wheelchair dependency have been estimated to be 5-10% for the two years, 20-25% of the 10-year risk and 70-80% for lifetime risk (Weinshenker et al., 1989), with a confirmation of the ten year risk calculated to be 24% (Ebers, 2001, unpublished data in Janssens et al., 2003a). Patients and partners were asked to rate their opinion regarding the seriousness of a wheelchair dependency, as well as their conjectures regarding their expectation of reaching wheelchair dependency Patients' mean perception of the 2-year risk was 22.5%, with 38.7% for the 10-year risk, and lifetime risk 54%. Thus, their perceptions of the 2- and 10-year risks were significantly higher than actual risks, while their perception of the 10-year risk was significantly lower than actual statistics. However, in a qualitative study using this same data (Boeije et al., 2004), patients reported that their responses of a 50% chance of wheelchair dependency in ten years was more indicative of their uncertainty than an actual demarcation of risk. This was clearly indicated by their responses to query: "it might happen or not" (as in a 50/50 chance) (Boeije et al., 2004, p. 861). Janssens and his team further hypothesized that such a response may suggest an "escape" from thinking about wheelchair

dependency, and thus an offering of a “neutral” 50% response (Janssens et al., 2003a, p. 291). Partners’ mean perceptions did not show to be significantly different; however, upon data inspection, substantial differences *within* partner dyads were quite different at all time points: that is, in some couples patients held the higher perception than their partners, while in others the trend was reversed. Another point of note is that patients with more functional limitations considered wheel-chair dependency to be less serious than more functional patients; however, no such difference was found in partners. Janssens et al. suggest further research on discordance between couples and its effect on the relationship, as well as the effect of uncertainty on couples and individuals facing illness.

Impact of Recent Diagnosis

It has been shown in previous studies that multiple sclerosis has a substantial impact on patients and their partners, interfering with daily activities, disturbing emotional well-being and quality of life, and affecting employment. However, these effects had only been shown for a population with illness duration of 8-16 years, leaving the effect of earlier phases of disease on patients and couples unexamined. Thus, Janssens and his colleagues (2003b) decided to study the emotional burden of recent diagnosis of MS on patients and partners. 101 newly diagnosed MS patients and their partners studied in order to assess the effect of the diagnosis on their emotional functioning. Examining patients with an average of 8 months after diagnosis, 34% of patients and 40% of partners had clinically high levels of anxiety, with 36% of patients and 24% of partners exhibiting high levels of distress. Approximately 50% of patients and partners showed significant levels of either anxiety or distress. Additionally, despite the researchers’ hypothesis that

quality of life would not be significantly reduced at the early stages of the disease, results showed that these scores were indeed significantly lower than the control population. Discussion of this phenomenon yielded two conjectures: first, perhaps patients were already exhibiting limitations due to their disability; second, due to the recent onset of disease, patients may be comparing their health status to their previous condition, thus focusing on the loss of ability rather than on the level of abilities themselves. Findings that even patients with mild limitations rated their quality of life poorly concur with this hypothesis. Finally, patients may feel more worried about the future, especially the implications of their initial disabilities. This is most relevant for those with high functional limitations, and may contribute to their high emotional distress; indeed, level of functional limitation was significantly correlated with emotional distress in patients (though not in partners). In general, patients and partners did not differ in levels of anxiety, but patients did demonstrate a greater tendency to avoid MS-related feelings, an aspect that may be due, in part, to the recent nature of the diagnosis. In addition, there were substantial differences in the psychological well-being within couples, though in some couples patients exhibited poorer psychological well-being, while in other couples partners were the ones in greater distress.

Mindfulness Meditation

Mindfulness: What, How, And Why?

Mindfulness involves sustained attention to ongoing mental content without comparing or in other ways judging what arises during periods of practice. As Grossman (2004) puts it, “mindfulness may be seen as a form of naturalistic observation, or participant-observation, in which the objects of observation are the perceptible mental

phenomena that normally arise during waking consciousness." Mindfulness, Grossman continues, involves the assumption that humans largely function in "automatic pilot" mode; nevertheless, with regular practice human beings are able to develop a sustained attention mode of observing their own thoughts. Such "moment-to-moment awareness of experience" provides more vivid and active participation rather than unconscious reactivity. Ultimately, this will allow a person to have more accurate perceptions of external and internal stimuli, leading to a greater sense of control over one's life choices (Grossman, 2004). By helping people regain control over their lives, the onus of their coping thus rests on them, rather than their having to rely on professionals who often do not have adequate time to truly provide for the biopsychosocial adjustments needed to cope with psychological and/or physical illness. In this light, mindfulness training, a "relatively brief and cost-effective program that can potentially be applied to a range of chronic illnesses and is able to effect a positive shift in fundamental perspectives toward health and disease should be of great interest" (Grossman, 2004).

Mindfulness-Based Stress Reduction (MBSR), created at the University of Massachusetts Medical School by Dr. Kabat-Zinn in 1979, is an expression of mindfulness tailored towards various elements of stress reduction. According to Grossman (2004),

> MBSR is a structured 8–10 week, group program with groups usually varying between 10 and 40 participants…. Each session covers particular exercises and topics that are examined within the context of mindfulness. These include different forms of mindfulness meditation practice, mindful awareness during yoga postures, and mindfulness during stressful situations and social interactions.

Kabat-Zinn and his team also pioneered a range of research surrounding the MBSR protocol, with research spanning the gamut of physical and psychological disorders and

MBSR's effect on them, launching a slew of research studies on MBSR and its beneficial effects on the body and the mind. Overall, research has shown that participants experience long-lasting improvements in both physical and psychological symptoms, as well as significant positive changes in health attitudes and behaviors and perception of self. Since the inception of MBSR in1979, more than 16,000 people, with a range of medical and psychological conditions, have completed the MBSR program. Additionally, more than 6,000 health-care professionals have participated in MBSR professional training programs in the United States and Europe, and more than 200 clinics around the world currently offer MBSR programs, including major hospitals such as Sloane Kettering, Duke University Hospital, and Yale Hospital (University of Massachusetts Medical Center website).

Mindfulness has been found to be an important tool for primary, secondary and tertiary prevention in both physical and mental health. As a tool for primary prevention, mindfulness meditation has been shown to have a strong effect on mood, stress reactivity and hardiness, memory, creativity, interpersonal functioning, and positive affect (Shapiro, Schwartz & Santerre, 2002). As a secondary prevention tool, mindfulness has been found to help borderline patients monitor their behavior and not act out or react as quickly as they would otherwise (Brodsky et al, 2003). As a tertiary treatment, mindfulness meditation training leads to significant improvement in T-cell count, anxiety, mood and self-esteem in a group of HIV positive men (Taylor, 1985). Below, I will summarize the literature on mindfulness and MBSR, as it applies to physical and psychological health.

Mindfulness and Psychological Health

Several studies have shown that mindfulness meditation, in itself (not as part of MBSR) has shown positive physical and psychological effects on normal populations. According to Carlson, transcendental meditation has been shown to decrease cortisol levels in populations of healthy volunteers (MacLean et al, 1994). In reviewing a number of relaxation practices for children, Chang and Hiebert (1989) found that teaching meditation to children in public schools increased academic performance. Cowger and Torrance (1982) found that meditation brought about significant change in invention, sensory experience, emotional expression, humor and fantasy in a group of college students. Sridevi, Rao and Krishna (1998) found that meditation resulted in a significant increase in positive personality growth. Emavardhana and Tori (1997) found that a single seven day Vipassana (mindfulness) meditation retreat resulted in significant increases in self esteem, self worth, self acceptance, and generosity, as well as changes in ego-defenses and coping skills, as compared with a control group. In testing the effects of MBSR on 78 medical students, Shapiro et al. (1998) found increased levels of empathy and decreased levels of anxiety compared with wait-listed groups. These findings were then replicated when the wait-listed groups received the same mindfulness meditation intervention. In 1995, Harte, Eifert and Smith compared meditation with running to measure their effects on hormone levels and mood change. They tested eleven elite runners and twelve highly trained meditators. Their results were somewhat surprising. When testing levels of corticotrophin-releasing hormone (CRH) after each activity, a hormone found to be correlated with positive mood changes, no significant difference

was found. Thus, the seemingly effortless “sitting” in meditation produced the same results that effortful running did.

Mindfulness and Psychopharmacology

Meditation has also been found to alleviate drug addiction, as well as to be used as a possible alternative to psychopharmacological interventions. In a large group of drug users, 83% of those who learned to practice mantra meditation gave up drugs altogether (Winquist, 1969). In another study, 138 experienced meditators compared to 59 subjects about to begin meditation and 39 non-meditators found that, besides showing “significantly less usage of all drugs, including alcohol, cigarettes and even coffee…. Meditators reported general increases in positive mood states, and ….they live in a less stressed, more regular life style than the typical American” (Schwartz 1973). In a study of psychiatric inpatients, Glueck (1973) taught meditation for several weeks, after which he found that he could greatly reduce psychotropic drug dosages and sedatives in a majority of cases as a result. This is important in that, compared to drug treatment, meditation relaxation does not bring about grogginess, but rather sharpens alertness. Indeed, meditation has been proven to induce faster reaction times (Appelle & Oswald, 1974), better auditory perception (Pirot, 1978) and more rapidity and accuracy in perceptual-motor tasks.

Mindfulness and Depression

In an attempt to discover ways of integrating mindfulness meditation into cognitive therapy, Segal, Williams., and Teasdale (2002) began observing Kabat-Zinn’s Stress Reduction Clinic at the University of Massachusetts. Segal, Williams, and Teasdale (2002) originally came to mindfulness training as a way to approach what they

called “the challenge of depression.” They found depression to be a challenging disorder to combat, because of its high tendency to recur. They describe the cognitive therapy understanding of the ongoing cycle of depression in the following way:

> Relapse involves the reactivation, at times of lowering mood, of patterns of negative thinking similar to the thought patterns that were active during people’s previous episodes of depression. Reactivation of these patterns is automatic…. At the heart of this state of mind is a particular “view” or “model” of depressive experience. Within this view, the self is seen (or more precisely, felt) as inadequate, worthless and blameworthy, and negative thoughts are seen as accurate reflections of reality (p. 67)

Like cognitive therapy, mindfulness-based cognitive therapy encourages patients to pay attention to their thought patterns and feedback loops. However, rather than trying to “do” something to “fix” these thought patterns, patients are encouraged to “be” with these thoughts and feelings. Ultimately, they did find that mindfulness training combined with cognitive behavior therapy produced significant reductions in relapse rates in patients with recurrent major depression. Other meditation studies have shown that people suffering from mild chronic depression or reactive depression may experience an elevation of mood once they begin a meditation practice (Carrington et al., 1980) although acute depressives have not been found to respond as well and are thus likely to discontinue meditation practice (Carrington & Ephron, 1975). Kabat-Zinn (1988) has thus begun studying ways of increasing compliance to mindfulness practice.

Mindfulness and Anxiety

In his 1973 dissertation, Daniel Goleman conducted a study in which he showed film footage of maiming accidents. He found that meditators returned to a state of calm significantly faster than non-meditators (Goleman, 1973 in Rama, Ballentine, & Ajaya, 1976). In another study, Goleman and Schwartz (1976) compared responses to lab

stressors in 30 experienced meditators to the responses of 30 control subjects. They found that while reactivity of meditators was initially heightened, meditators' heart rate and skin responses habituated more quickly. They also reported lower levels of subjective anxiety than non-meditators. Puryear, Cayce and Thurston (1976) tested to two groups, a control and a treatment group. After 28 days of meditation, the treatment group reported a highly significant reduction on the IPAT Anxiety Scale scores but no significant change on the Mooney Problem Check List.

In his book, *Full Catastrophe Living*, Kabat-Zinn (1991) suggested that the moment-to-moment focus of mindfulness seems to calm and contain the fight-or-flight sympathetic nervous system response during stress. This calmness and clarity allow one to "'respond' to potentially anxiety-producing situations with greater effectiveness rather than to 'reach' with escalating panic or fear, which invariably feeds feelings of loss of control" (Miller et al., 1995, p. 197). Further, the more one practices mindfulness formally in times of little or no stress, the more they are likely to be able to utilize the skills in highly stressful times. Mindfulness training allows one a practical road map to "disentangle from reflexive behaviors and reactions that have their roots in past experience" (Miller et al., 1995, p. 197), creating an alternative route for responding to stress.

In 1992, Kabat Zinn et al. embarked on a now oft cited study to examine meditation's effect on clinically anxious populations. 22 subjects were screened with DSM III R criteria for generalized anxiety disorder, panic disorder, or agoraphobia. Weekly assessments, including self-ratings as well as therapist ratings were obtained prior to and during the MBSR course, with monthly assessments for three months

following the course. Significant reductions in anxiety and depression scores were reported after treatment in 20 out of the 22 subjects. In addition, there was a significant reduction in number of panic attacks from pretest to post-test. Upon three month follow-up these changes were maintained. This improvement was observed both through self ratings as well as through interview ratings.

As an adjunct to his original study of mindfulness' effect on anxiety (see above, Kabat-Zinn et al, 1992), he joined several other researchers to examine the long-term effect of this intervention on the same subject population (Miller et al., 1995). Thus, three years later, the research team examined 18 of the original 22 subjects, reporting that the original improvements shown post-treatment were maintained at the three year follow up, showing significant improvements in each measure. In addition, qualitative interviews spoke to the importance of the mindfulness intervention to their life, with 10 being "very important," twelve participants rated the course a 7 or greater, with five of these rating it a 10. When asked about whether the course had a "lasting value" for them, 16 of 18 responded that it did, with one subject responding that s/he was "not sure," and one not responding. Such improvements were explained by the fact that mindfulness meditation

> can abate or short-circuit fight or flight reaction characteristic of the sympathetic nervous system, particularly in stressful or anxiety-producing social situations where it is non-adaptive. Mindfulness and the associated calmness, clarity, and stability of mind which are associated with it allow one to 'respond' to potentially anxiety-producing situations with greater effectiveness rather than to 'react' with escalating panic or fear, which invariably feeds feelings of loss of control (Miller, Fletcher and Kabat-Zinn 1995, p.194).

In addition, they add that meditation not only serves as useful relaxation tool for times of stress, but it can also be utilized as a method of prevention:

> Anecdotal reports from thousands of patients in the SR & RP over the past 16 years suggest that the more one practices formally at home in times of low stress, the more likely the transfer to other in vivo situations of high stress (Miller, Fletcher and Kabat-Zinn 1995, p.194).

It is important to note that in comparing subjects who were taking benzodiazepines or anti-depressants prior to the course with those who were not, there were no significant differences between the two groups in their continuation of the mindfulness exercises, as well as in the results. Further, of the seven subjects who had been undergoing therapy prior to the mindfulness course, four had discontinued therapy at the three year follow-up. Of the 18 subjects interviewed at the follow-up, ten continued to practice formal mindfulness meditation, and 16continued practicing informal meditation, with four using it "often," 11 using it "sometimes," and only one "rarely" using the mindfulness skills. In addition to the original study subjects, 39 "nonstudy" subjects who had received the same intervention were given pre and post measures of psychological symptomatology. Results showed similar improvement in this cohort, thus eliminating the possibility that the weekly phone reports and data collecting of the research protocol created a "quasi-therapeutic" role in the research subjects' improvements. Nevertheless, it is important to note, as Miller et al. (1995) state, that the research design lacked a formal randomized control group for comparison, and the number of subjects studied was small.

Kabat Zinn et al. (1997) decided to determine the efficacy of various aspects of the MBSR program on symptom diminution in differing anxiety types. Contrary to a previous theory (Davidson & Schwartz 1976), Kabat-Zinn et al discovered that subjects whose anxiety was predominantly somatic found most comfort in the more cognitive meditation practice, whereas those whose anxiety was found to be predominantly

cognitive seemed to have a predilection towards the more somatic Hatha yoga practice. The body scan, which encompasses both cognitive and somatic components seemed to be preferred similarly and to an intermediate degree by both groups. However, since most anxiety patients seemed to be balanced in cognitive and somatic elements of their anxiety, Kabat-Zinn et al suggest that MBSR, in its varied components appealing to various modes of anxiety, is a good fit for most types of anxiety. Further, regardless of anxiety type, a course of MBSR showed significant improvement in overall anxiety for participants. Thus, it "may be more therapeutically beneficial and cost effective in heterogeneous populations of medical patients than matching individual patients to specific relaxation techniques on the basis of their anxiety response modes" (Kabat-Zinn et al 1997, p. 108).

Shapiro et al. (1998) utilized a randomized, controlled study, in a non-patient population of medical and premedical students. They found that levels of state and trait anxiety and depression were reduced, with an increase in empathy after the MBSR intervention. The change in trait anxiety is important to note, since a later study in a clinical population of patients with MS found only a change in state anxiety, and not trait anxiety. Certainly, this could be due to the difference in populations, for in the above study the population began with significantly lower than normal scores in depression and anxiety. Thus, it could be that it takes more time for a clinical population to change, and/or to perceive change in trait anxiety.

Mindfulness and Physical Health

Mindfulness and Psoriasis

In a study of 37 patients with moderate to severe psoriases, utilizing phototherapy (UVB) or photochemotherapy (PUVA) Kabat-Zinn et al. (1998) assigned one group to follow a guided mindfulness meditation during their treatment, whereas a control group received the light treatments alone, without the mindfulness component of the intervention. Photographs of each group were rated by dermatologists, before and after treatment, in terms of skin status. Using statistical analysis, the photos showed that the meditators' skin cleared at approximately four times the rate of those who received the light treatment only. An earlier and smaller study (Bernhard, Kristeller and Kabat-Zinn, 1988) also found similar results. Although both studies had small samples Kabat-Zinn suggested that the results demonstrate that the mind can positively affect the healing of a specific disease. Also, this kind of psychological participation of the patient during the medical treatment can lead to better results with fewer treatments. Third, as Kabat-Zinn et al. (1997) note, social support that would normally be inherent in a group or intervention was excluded and thus "cannot be a major factor in the observed outcome" (p. 152).

Mindfulness and Cancer

In a group of breast cancer patients who had sleep complaints due to disease-related anxiety, both MBSR and cognitive interventions helped the sleep disturbance, but MBSR led to stronger and longer lasting effects. Further, MBSR was associated with enhanced quality of life and decreased stress symptoms in breast and prostate cancer patients, and resulted in possibly beneficial changes in hypothalamic-pituitary-adrenal

(HPA) axis functioning (Carlson, 2004). Carlson (2004) also found significant improvements in quality of life, symptoms of stress and sleep quality in cancer patients who were used mindfulness meditation, as well as increases in T cell production and an overall shift in their immune profile from one associated with depressive symptoms to a more normal profile.

In 2000, Speca et al. conducted a study with 109 cancer patients of heterogeneous type and stage. Participants were randomly assigned, with 61 in the experimental MBSR group, and 48 in a wait-list control group. Group participants completed measures in stress levels and mood prior to the intervention, and immediately following the seven week MBSR course. Results showed that participants experienced a 65% reduction in total mood disturbance, as opposed to 12% reduction in the control group. Additionally, the number of minutes of at-home mindfulness meditation practice affected the amount of change in mood; those that practiced more at home experienced greater alleviation of mood disturbance.

In 2001, Saxe et al. conducted a study on the effect of MBSR and diet changes on prostate cancer. The only MBSR study to include couples, significant others were invited with the intention of compliance, especially in dietary adherence. Results indicated that the rate of the increase of PSA decreased in 8 out of the 10 patients in the study, while three exhibited decrease in absolute PSA.

Carlson et al. (2004) conducted an uncontrolled trial of MBSR focusing on early-stage breast and prostate cancer. The study included 42 participants (33 breast cancer, 9 prostate) who were at least three months post treatment. Measures of mood, quality of life, stress, and health behaviors were assessed. Additionally, blood samples were

provided for immune and hormonal analysis pre and post intervention. Contrary to MBSR research (see above), no mood changes were observed in participants; however, improvements were shown in overall quality of life and stress, as well as in use of caffeine, appetite and exercise. No additional changes were shown in cancer-related symptoms, such as fatigue, pain and nausea.

A similar study was conducted by Shapiro et al. (2003), focusing specifically on sleep disturbance for women with stage II breast cancer, within two years post-treatment. 63 women were randomly assigned either to the MBSR intervention or to a "free choice" stress reduction group. Participants kept sleep diaries at one week, three months and nine months after the MBSR course. 54 participants completed this follow-up data. However, results showed no change in sleep quality in either group, despite some evidence that intervention participants who engaged in informal mindfulness techniques were more likely to feel refreshed after sleep.

Mindfulness and the Immune System

In 2003, Davidson et al. measured brain activity in 25 subjects, pre, post, and at four months after an MBSR group. They compared these measures to a wait list control group of 16. Results showed a significant increase in the activation of the left side anterior region. This area of the brain has been associated with positive affect. Additionally, since this area of the brain has been associated with enhanced immune function (Davidson et al., 1999), Davidson and his team vaccinated both groups at the end of the eight-week course with an influenza vaccine. The group of meditators showed significantly higher levels of antibodies to the vaccine than the control group, thus

showing that the MBSR intervention not only increased positive affect, but also significantly affected the body's immune response system.

Mindfulness and Chronic Pain

In 1984, Kabat-Zinn and his colleagues studied 90 chronic pain patients who had gone through the stress reduction mindfulness training at University of Massachusetts Medical Center. Pain disorders were lumped into three categories: low back pain, headaches, and neck and shoulder pain. Results showed that the degree of improvement post-course was independent of diagnosis and pain severity, as well as gender and referral source, suggesting a generalized applicability of the intervention. Significant improvements on all measurements were for the most part maintained in the follow-up period of 2.5 months to 7 months. In addition, improvements in negative body image and pain symptoms were also maintained at significant levels 12 to 15 months post-intervention. As an adjunct to the 1984 study, Kabat-Zinn et al (1986), decided to correct the "paucity of follow-up studies" (p. 159), by conducting a follow-up study with 225 chronic pain (the original 90 plus additional numbers who enrolled after the fact) patients who had gone through the University of Massachusetts Medical School MBSR program. In addition to extending the 15 month follow-up of the previous study to up to four years, this study aimed to assess the degree to which subjects felt the intervention had a lasting value on their lives, as well as to assess follow-up compliance, and to determine the extent to which compliance correlated with degree of improvement. The study also compared responders with non-responders, based on initial post-intervention assessments. This study confirmed the earlier finding that body image, medical symptoms, and psychological symptoms, improved as a function of the mindfulness eight week

intervention period. Additionally, it extended the follow up to four years, showing a longitudinal realization of the improvements. When asked if the course was of "lasting importance", over 85% of the participants asserted that it was. This was attributed to subjects' learning control over their pain and stress (40%) and "a new outlook on life" (20%, p. 168). Another item of note is that there was a high instance of compliance, with over 93% reporting using at least one of the meditation techniques at least some of the time, and between 58-83% of responders specifically continuing to formally meditate. However, researchers found only a modest relationship between compliance rate and improvements, confirming an earlier study that showed that it was not how much people meditated but whether they did (Libo & Arnold, 1983).

Melzack and Perry (1975) noted that, after a biofeedback and hypnosis session, individuals experienced relief from pain for several hours after the intervention. So too, Kabat-Zinn (1982) found a similar "phenomenon of carry over" as a result of the mindfulness meditation intervention (p. 44). Holroyd and Andrasik (1980) found that when patients were taught to recognize the onset of their headache symptoms, they were able to change the ways they coped with the stressful situation even though they were never taught coping skills. Holroyd and Andrasik thus concluded that

> it may be less crucial to provide clients with specific coping responses than to insure they monitor the insidious onset of symptoms and are capable of engaging in some sort of cognitive or behavioral response… this response need not be relaxation and in certain situations where… in appropriate… should not be relaxation (1980).

Thus, as Kabat-Zinn notes, "these observations imply that moment to moment mindfulness may itself be the underlying coping mechanism" (p. 44). In 1997, Astin used a randomized, controlled study design to examine MBSR's effect on chronic pain. Astin

found significant reductions in depression and anxiety. He also found that patients who participated in MBSR perceived an increased sense of control, as well as higher scores on Inspirit, a measure of spiritual experiences. Sagula and Rice (2004) explored the effectiveness of MBSR on the grieving process associated with patients who suffer from chronic pain. Utilizing Schneider's (1994) model of grieving, they delineated seven stages of grief, with the first stage being awareness of what one has lost, and the final stage involving the reformulation and transformation of "what is now possible" (p. 335). Certainly, Schneider's first stage is included within the very tenets of mindfulness meditation, in that mindfulness is defined as an "awareness of the present moment." Results indicated a significant improvement in coping and awareness, characteristic of the early grieving stages, though they did not as a group progress to the later stages of "growth." This may be due to a couple of reasons. First, the authors note that although the stages are delineated in a progressive fashion, they do not always proceed linearly. Additionally, an eight week intervention may not represent a long enough period of time to move through the stages. Finally, due to the increased awareness provided by the MBSR intervention, the consistent re-examination of the present moment may instigate a recycling process through the initial stages, each time "new information or a new perspective" arises (Schneider, 1994, p. 66). Finally, significant decreases were shown in participants' depression and anxiety state scales, with no significant decrease in the anxiety trait scale. Thus, it could also be that eight weeks is not long enough for a person to re-examine his or her trait, and that this is something that would have to be specifically explored in a longer term study.

Health-Related Quality of Life and Mindfulness

Riebel and his colleagues (2001) examined MBSR's effect on "health-related quality of life," as well as physical and psychological symptoms of a patient population experiencing a range of physical disorders (p. 183). The population consisted of 136 students in twelve separately running MBSR classes between 1997 and 1999, derived from classes that had been open to anyone who wished to enroll. Results indicated that significant improvements were observed on all indexes, thus showing enhanced health-related quality of life, measured by physical function and well being. Additionally, there were significant positive changes in anxiety and depression of participants. One year follow up data indicated a continuation of these results.

Grossman and his team (2004) conducted a meta-analysis on the health benefits of MBSR. Initially examining 64 studies of MBSR, they chose 20 studies that met inclusion criteria, including sufficient intervention information, adequate and well executed statistical and quantitative evaluation; additionally, studies had to have MBSR as a central component and had to be focused on health-related issues. They found similar effect sizes 0.5 ($P < .0001$) both in controlled and uncontrolled studies, in an even distribution. Ultimately, despite the small number of included studies, Grossman et al. (2004) conclude that MBSR's positive effects help a heterogeneous population in both clinical and non-clinical settings.

Compliance

Since medical patients are often referred by their doctors to behavioral clinics for training in behavioral and relaxation techniques, yet there is "little information in the

literature" (Kabat-Zinn & Chapman-Waldorp, 1988, p. 334) about the compliance rate of these programs, Kabat-Zinn and Chapman-Waldorp decided to examine the compliance of the participants in the mindfulness program at University of Massachusetts Medical Center. The study was created both to obtain information about compliance in such programs and to identify possible predictors of program completion. Participants in the study were 784 patients who had been referred to the clinic by physicians for stress reduction training. Presenting problems varied, with the researchers assigning subjects to two cohorts, a chronic pain group and a stress reduction group. In order to qualify for the former group one would have had to have suffered with chronic pain for at least six months, and to have come to the clinic specifically for pain alleviation. Even cancer patients who came to the clinic for stress reduction were assigned to the second group. Subjects were enrolled in the same groups without regard to diagnosis or reason for referral. Of those referred, the only presentation that was turned down from the training group was active suicidality or psychosis, which occurred in only 1% of subjects interviewed. Subjects were told about the nature of the program, including the amount of commitment needed to enroll, and the challenge they should expect in keeping up with the 45 minute per night homework. As Kabat-Zinn and Chapman-Waldrop write, "no attempt was made by the staff to 'sell' the program (p. 337)." Only 9.8% of interviewees decided not to enroll in the program. 76% of subjects completed the program.

The study indicated that two major factors significantly differentiated completers from noncompleters when evaluating the two cohorts separately: First, females with chronic pain were twice as likely to complete the study as males with chronic pain. Secondly, among the stress cohort, those who rated highly on the obsessive-compulsive

sub-score on the SCL-90-R were more likely to complete the program. Of the pain cohort, men who had higher OC scores showed a tendency (though not significant) to complete the intervention when compared with lower OC scores. Another tendency that did not reach significance is that those individuals who had experienced chronic pain for a longer period were more likely to complete the program. The authors' hypothesis regarding this aspect is that perhaps they had had a longer course of traditional medicine, in which they were not given much autonomy, and that they were now perhaps ready to take on a program that incorporated "self responsibility and self regulation" (Kabat-Zinn & Chapman-Waldrop, 1988, p. 347). The authors suggest examining a measure of internal vs. external locus of control for future studies to examine this hypothesis further. When evaluating why there was such a high compliance rate in this study, the authors point both to the attitude of the interviewers in presenting the subjects with a "personal challenge," as well as to the variety of modalities presented through the course. Another important piece that the authors specify as a strength of the program is the variety of subjects' medical needs. According to the authors, this variety allows the group to emphasize the hardiness of their inner resources, rather than to focus on their ailment. This is important to note due to the specificity of the diagnosis of the population of the subjects of my own study.

MBSR and Couples

Until recently, the only MBSR study that included couples was the prostate cancer study mentioned above (Saxe et al., 2001). As noted, that study included couples, but focused on the patient and thus did not assess the effect of including the partners in the intervention.

In 2004, Carmody created another study specifically targeting couples with an MBSR intervention. An adaptation of MBSR, Carmody created the concept of Mindfulness Based Relationship Enhancement (MBRE). This study differed in several ways from the current study. First, it did not target couples dealing with illness. In fact, couples were specifically screened to be "nondistressed" couples. Secondly, several couple interventions were put into place as part of the course curriculum, and homework was often assigned for the couple as a whole, e.g. partner yoga rather than individual yoga, lovingkindness couple meditations, more communication skills, etc. Third, in addition to the specific demographics noted above, other demographics differed significantly from this population, including average length of marriage (11 years as opposed to the 20+ in this sample), average age, (ten years younger than this population), and less intra-group variability (sexuality, age, race, etc.). Results of the MBRE study pointed to increased couple satisfaction as measured by the Quality of Marriage Index (QMI; Norton, 1983), which was deemed equivalent to the DAS (Heyman et al, 1994).

Limitations of Mindfulness and Health Research

Despite this seemingly exhaustive list of studies, Shapiro, Schwartz and Santerre (2002) do note that there the literature could be more precise:

> Many of these studies are over a decade old, do not use rigorous research design (including lack of randomization, lack of follow-up, and imprecise measurement of constructs), and sometimes are based on small samples. Researchers often failed to report what type of meditation technique was taught, or the length and intensity of the practice. Also several of the studies retrospectively compared meditating persons with those in control conditions, which yields correlational but not causal inferences (p. 634).

In addition, Rivers and Spanos (1981) found that pre-test self esteem and somatic measures predicted voluntary participation as well as attrition rate in meditation, thus

suggesting that meditation volunteers are, to a certain extent, self selecting. If this is true, then it could be that only a select group would be most likely to benefit from meditation practice. Another critique of these studies is that while there has been extensive research in this field, often different types of meditation are lumped together when reviewing its efficacy. In fact, different types "of meditation may have very different effects on the practitioner and thus may have different clinical applications" (Bogart 1991, p. 385).

Another important point is that due to the variety of therapeutic elements within the MBSR intervention, it is sometimes difficult to decipher which particular therapeutic aspects of the MBSR intervention directed the positive results. For example, social support and emotional expression, two important elements found in the MBSR group as well as in most support groups, have been shown to lead to physical and psychological improvements in the past (Ornish 1998). Patient expectancy has also been shown to influence medical outcomes (Harrington 1999, Carrington, 1980). In Reibel and her team's study of MBSR's effect on quality of life (2001), it was noted that 100% of MBSR participants in this study had anticipated a reduction in tension, and 80-90% anticipated a reduction in physical symptoms. While indeed these participants' expectations were met, it is not entirely clear how much of the positive results is related to a self-fulfilling prophecy.

Multiple Sclerosis and Mindfulness

While, to date, there have not been published studies utilizing the full MBSR intervention with patients suffering from MS, I will summarize two studies that have utilized aspects of MBSR as treatment interventions for MS populations, yoga and

mindfulness of movement. The results and details of these studies provide insight into the possibilities of aspects of the MBSR intervention for this population.

Yoga and Multiple Sclerosis

According to Bourdette and her team (2004), 30% of 1,980 survey respondents with MS had taken yoga, and 57% of these reported the yoga to be "very beneficial." Thus, Oken and her colleagues (2004) decided to conduct the first randomized controlled trial of yoga for people suffering from MS. 69 subjects with clinically definite MS were randomly assigned to three different groups for six months: weekly Iyengar yoga classes with home exercise, weekly stationary bicycle classes with home exercise, or a wait-list control group. The aim of the study was to examine the effect of yoga and exercise on fatigue, mood, cognitive function and quality of life on patients with MS. Measures were given at baseline and at six months and included measures on alertness, attention, and health related quality of life. While the yoga and exercise program produced no significant changes on alertness, attention, or cognitive function, they both produced equally significant effects on improvement of fatigue. The researchers note that socialization, placebo and self-efficacy effects may have also played into the positive results of the two programs. However, it is important to note that there were only 20 subjects per group. The researchers note that this small sample size may therefore not rule out the possibility that a larger subject pool may reveal mood and cognition effects.

Mindfulness of Movement and Multiple Sclerosis

Previous therapeutic interventions for MS have mostly focused on drug trials (Holliday & Benfield, 1997), or in-patient rehabilitation programs which are only available in major hospitals (DiFabio, 1998). Petajan and White's(1999) review of the

effects of exercise for MS patients conclude that exercise is indeed beneficial for MS patients, as long as it does not overload the muscles; the review recommends that future research examine the effect of more “meditative, mindful” exercise systems, such as Tai chi/Qi Gong (Mills & Allen 2000, p. 425).In line with this, Mills & Allen (2000) created a pilot study with sixteen matched MS patients, eight of which they randomly assigned to an experimental mindful movement group, and eight of which they continued with treatment as usual for their control group. The mindfulness movement protocol consisted of six one-on-one weekly meetings with Tai Chi / Qi Gong movements, and awareness training in muscle tension through the mindfulness technique utilized in MBSR, called “body scan.” A previous study by Mills and his team (Mills, Allen & Carey-Morgan, 2000) showed preliminary findings for the experimental group, with this study serving as a 3-month follow-up pilot. Because the study involved physical exercise, those who were physically incapable of holding a pencil, and/or unable to make a commitment to regular practice with audiotape and videotape, were excluded from the study; however, despite their relative functioning ability, participants had to be experiencing at least one symptom which affected their day-to-day life. The sessions included: “development of awareness of muscle tension, of spinal alignment, of posture, of breathing, of balance, of shifting weight, and of co-ordinated movement” (Mills & Allen, 2000, p. 426). Results showed that the mindfulness of movement group exhibited a significant and consistent pattern of improvement, as opposed to the deterioration showed by the control group; this was true both at post-therapy time as well as in the 3-month follow-up, and when rated by participant or by his/her relative or friend. Nevertheless, it is important to remember that this study, with its small n, is simply a pilot study, and may not be strong enough

evidence to generalize. However, results do suggest several possible therapeutic benefits: first, physical guidance, specifically with "a general 'ethos' of mind-body awareness" was applied, encouraging subjects to "'inhabit' their body in a more alive way" (Mills & Allen, 2000, p. 430). Such "mental imagery can have a significant effect on motor performance" (Mills & Allen, 2000, p. 430). Mindfulness training can also help shift the focus from what others think to the body at the present moment, allowing one to both be relaxed and alert as s/he attempts motor functioning.

Conclusion: MBSR for Couples Facing MS, A Rationale

As is described, there are many psychological factors affecting the level of distress in patients with MS, at times having little to do with actual levels of disability (Mullins et al., 2001). Additionally, there is much data suggesting the effect of chronic illness on a couple or family, and vice versa (Rolland, 1984, Steinglass, 1988). As a result of such research, researchers suggest interventions that are geared towards "both carer and care receiver," specifically addressing both members of the couple at the same time, rather than separately (Pakenham, 1998). Schwartz & Kraft (1998) further underscore the idea that couples facing chronic illness should be treated as a unit. Nevertheless, as Pakenham (1998) notes, no such interventions have been researched.

Other interventions recommended through the literature include "stress reduction techniques such as relaxation and imagery," as well as the mobilization of "social supports" (Wineman et al., 1996, p.59). Mills & Allen (2000) concur, suggesting that mental imagery can help MS patients connect to their bodily changes, and thus abate some of the physical challenges. McNulty et al. (2004) suggest an intervention that addresses spirituality, an aspect shown to be increased through an MBSR intervention

(Astin, 1997). Finally, other researchers (Mullins et al., 2001, Janssens, 2003a) suggest activities that lessen the perceived lack of control caused by uncertainty.

MBSR has been shown to lower psychological distress, including depression (Segal., Williams., & Teasdale, 2002) and anxiety (Goleman & Schwartz, 1976, Kabbat-Zinn, 1991, Kabat-Zinn et al., 1992, Miller et al., 1995), to increase sense of control (Astin, 1997), and to increase awareness. Additionally, it has been shown to alleviate distress associated with chronic pain (Kabat-Zinn et al., 1984, 1986, Astin, 1997, Sagula & Rice, 2004), as well lessen psychological distress associated with several chronic illnesses, including psoriasis (Kabat-Zinn et al., 1998), fibromyalgia (Astin et al., 2003), HIV (Taylor, 1995), and cancer (Speca et al., 2000, Saxe et al., 2001, Shapiro et al., 2003, Carlson, 2004). It has also been shown to cause specific changes in the brain that increase happiness and that lead to a stronger immune system (Davidson et al., 2004). Since much of the distress associated with MS has been linked to uncertainty, and the discomfort associated with high uncertainty, the central question of this study was whether Mindfulness Based Stress Reduction, administered to couples who have a member suffering from MS, could abate the effects of uncertainty.

Additionally, by offering a participatory intervention such as MBSR, one that creates “a personal challenge” (Kabat-Zinn, 2000), the hope was that it would not only instigate a sense of self-efficacy (Bandura, 1977, Kabat-Zinn, 2000) but also an alliance within the couple, giving them a program to work through together. MBSR for couples incorporated many of the above clinical suggestions that have arisen from the research. This study took the recommendations above, and, for the first time, applied them both patients and partners dealing with the infliction of Multiple Sclerosis on their lives.

CHAPTER THREE

Methodology

As described in Chapter I, this study explored the effect of an MBSR intervention on the tolerance of uncertainty of couples with one couple member diagnosed with Relapse Remitting MS. Chapter II outlined the existing theory and empirical research on chronic illness within families, couples and MS, uncertainty and MS, and the effects of MBSR. In this chapter, I provide a description of the sample and population, procedures, intervention, and measures associated with this study.

Sample and Population

An estimated 400,000 Americans have MS. Most are diagnosed between the ages of 20 and 50 and about two-thirds are women (National MS Society Website, 2008). Of this population, 20,000 MS patients live in Illinois (Illinois Chapter of the National MS Society website, 2008), with 8,000 living in the greater Chicago area. This study focused on a convenience sample of participants who live in the Chicago area. Two groups of treatment participants were recruited**.** Participants were recruited formally through an "email blast" sent out by the Chicago area National MS Society. Those who responded first and were available for the first treatment class joined Treatment Group One (T1), a sample of eleven couples. A second email blast was sent out several months later, resulting in the group for Treatment Group Two (T2), a sample of fourteen couples. Treatment participants received $100 per couple for joining the course to help alleviate transportation fees. Additionally, some participants who had not been able to join T1 then

joined T2. All couples had a couple member diagnosed with Relapse-Remitting MS. Below are the inclusion and exclusion criteria for subjects:

1. Both members of the couple were fluent in English.
2. One member of couple dyad was diagnosed with Relapse-Remitting MS.
3. The MS patient must have been physically able to attend weekly program classes.
4. The couple must have been living together or married for at least one year.
5. The couple must have been willing to commit to the 8-week course intervention, as well as to approximately 45 minutes per day of course "homework".
6. The couple needed to complete study tools before and after intervention.
7. Potential participants were screened for suicidality, active substance abuse, severe social anxiety, and/or major psychiatric diagnoses that could interfere with course participation.

Data Collection

Participants for this proposed study were recruited from a convenience sample of the Chicago-area membership pool of the Multiple Sclerosis Society. Participants were recruited through an online posting for the Illinois chapter of the Multiple Sclerosis Society website. A second source of recruitment was through one-time informational introductory sessions about MBSR for couples with MS. These sessions were held at various Chicago MS Society Support Groups that took place at a variety of hospitals within the Chicago area.

Interested potential participants were instructed to contact me directly via email or phone. At that point, an initial telephone meeting was set up in order to assess potential participant eligibility as defined by the inclusion criteria and participant commitment to

course protocol. In that initial meeting, I described the intervention in detail. I also explained about confidentiality issues: Each participant would be assigned a code after the initial pretest measures, which would link to his or her name. The master file would be stored in a locked file cabinet, separate from the data, and only I would have access to the key. All data and files would be kept in a locked file drawer in my home office.

Transcription of initial entry interviews and data collection was handled with respect to the confidentiality of the participants. Once data was collected and analyzed, I stored the data for possible use in further research. This data was stored in my home in the locked file cabinet to which only I have access. Potential participants were invited to ask questions. Once both of the potential participants within in the dyad were satisfied with the answers, acknowledged understanding the study, and signed the consent form (see Appendix 1), the couples were accepted into the proposed study.

Initial measures were administered two weeks before the first day of the course via email. Participants had to send back completed measures prior to the course via email and/or fax, or they were not allowed into the course. For those who emailed their responses, hard copies of the consent form had to be turned on the first day of the course. The second set of measures was administered on the last day of the course, at the course's end. The second set of measures was administered by a research assistant (RA) whom I hired and trained regarding the administration of the measures and confidentiality of the proposed study. After a brief introduction of the RA and reminder of confidentiality and participant rights, I left the room with the assurance that I was waiting in the next room if needed to answer questions. At that point, the RA presented the forms to the couples.

The forms were presented to the couple in a sealable envelope. Each form had sealable codes on it in place of names. The RA informed the participants to fill out the forms and, upon completion, to place them in the envelope, and seal and return it to the RA. The RA will then return the sealed envelope to me, thus assuring participant confidentiality.

Procedure

The MBSR treatment was administered to two different groups in two sets of courses, T1 and T2, with half of the participants in one course and half in the second. Determination of who took which course was made based on time availability of the participants and order of course sign-up. Two separate time slots were available with a maximum of 13 couples in each course. Once the maximum number was reached in the first course, the course was closed; at that point, participants were assigned to the alternate time slot, upon their availability and willingness.

Minimal risks were expected to be associated with this proposed study. The testing measures required participants to answer a variety of questions related to personal anxiety levels, as well as to thoughts and feelings regarding MS and their daily life events. As a result, participants may have become aware of issues related to stress and well-being in their lives. The most physical element of the MBSR intervention is the gentle yoga practice, which involved slow, methodical movement that could be adapted to a range of physical abilities. In a study comparing stationary cycling in MS patients to Iyengar yoga, a relatively challenging type of yoga, no negative effects were reported (Oken, 2004); rather, both vigorous yoga and cycling produced similarly positive results with a significant decrease in patient fatigue. Both cycling and Iyengar yoga are far more

advanced forms of exercise than the gentle yoga utilized in the MBSR intervention. According to Bourdette et al (2004), 30% of 1,980 survey respondents with MS had taken yoga and 57% reported the yoga to be “very beneficial”. Nevertheless, for safety’s sake, all participants were required to provide a medical clearance form and a Hold Harmless form was signed along with the consent form.

Mindfulness Based Stress Reduction (MBSR)

MBSR is a “systematic patient-centered educational approach” which relies on intensive training in mindfulness meditation through a series of progressive exercises, both in and out of class (Kabat-Zinn, 1996). An eight-week, step-by-step intervention, the protocol was developed by Kabat-Zinn (1990) at the Stress Reduction Clinic of the University of Massachusetts Medical Center and was immediately used in myriad research studies (Kabat-Zinn et al, 1992, 1996, 1997, 1998, 2001). The model had been used both in medical and non-medical settings internationally, including hospitals, schools, prisons, and in corporate arenas (Kabat-Zinn, 1996).

The Intervention

Although the MBSR protocol from CFM consists of a detailed, session-by-session recommendation, the program founders reiterate the importance of “the moment” in the delivery of the protocol, allowing for flexibility in intervention order based on the needs of the teacher and the group at the present time. The general outline of the program is:

1. Individual pre-program intake/assessment interviews (45-60 mins) or group orientation sessions (120 minutes)

2. Eight weekly classes (2.0-2.5 hrs each)

3. An all day silent retreat during the sixth week of the program

4. Formal Mindfulness meditation methods:

    a. Body Scan Meditation: While the participant is lying down or in a comfortable position, a set of guided instructions is given either live or through audiotape or CD. Through the instructions, the participant is guided to take notice of each body parts, without judgment or reaction.
    b. Gentle Yoga: Meditation through movement, in which participants are encouraged to take notice of their body as it moves into various gentle postures.
    c. Sitting Meditation: Progressing from structured to unstructured throughout the course, this meditation involves increasing lengths of time, in which subjects sit silently, in a still position, while adhering to the course leader's instructions. At varying times, instructions may be given before and/or during meditation and may include: awareness of breath, body, sensations, thoughts, and/or emotions. Near the end of the course, choiceless awareness, or insight, meditation is introduced, in which the subject has freedom to follow each moment with awareness.
    d. Walking Meditation: Introduced during the day-long event, walking meditation is a slow, mindful walking, in which subjects break down and notice each piece of their steps.

5. Informal Mindfulness Meditation methods:

    a. Awareness of Pleasant and Unpleasant Events: Initially a homework assignment in which participants are asked to keep a log of events. This becomes an informal awareness model. Through this awareness, participants take note of accompanying thoughts, feelings, and sensations, without necessarily acting on these phenomena.
    b. Awareness of Breathing: As participants go about their day, they are encouraged to stop, take notice of their breath, noticing its quality and where they notice it in their body, etc.
    c. Awareness of Routine Activities such as eating, driving, walking: taking time to take notice of these events, doing them "mindfully" rather than rushing through the moments

6. Daily home assignments: A minimum of 45 minutes per day of formal mindfulness practice and 5-15 minutes of informal practice are assigned, 6 days a week, for the course duration.

7. Large and small group discussion, as well as couple discussion, is encouraged within the course, in order to explore the integration of course skills into daily life, exploring difficulties in completing homework assignments, questions, etc.

8. Psycho-education: The origin of stress in the body and the history of stress research is presented. Disease specific elements are also presented. The history of MBSR, its Eastern origins, and the goals of the course are also explained.

9. Post-program assessment and brief exit interviews (45-60 minutes) is conducted within 2 weeks of the last date of the course.

Teacher Qualifications

The Center for Mindfulness (CFM) at the University of Massachusetts provides intensive training for instructors of MBSR. The minimum training level required for recommendation as an instructor is completion of the 66-hour practicum internship through CFM. More advanced teachers can apply for the selective Teacher Development Intensive, a 92-hour program, which provides group and individual advanced MBSR training.

In the summer of 2005, I completed the Practicum Internship and, in the winter of 2006, I completed the Teacher Development Intensive. Thus, I have met qualifications necessary to teach the MBSR intervention for this proposed study.

Measures

The first measure, the State/Trait Anxiety Index (STAI- Form Y; Spielberger, 1983), is a 40 item self-report measure, which includes separate measures of state (SAI, 20 items) and trait (TAI, 20 items) anxiety, and are measured on a four point scale from

one to four. State anxiety may fluctuate over time and can vary in intensity. In contrast, trait anxiety refers to a general tendency to respond with anxiety to perceived threats in the environment. Ten of the State and nine of the Trait items are reverse-scored. Scores on the STAI have a direct interpretation: high scores show high levels of trait or state anxiety and low scores indicate lower levels. Percentile ranks and standard (T) scores are available for male and female working adults in three age groups (19-39, 40-49, 50-69). It takes between 10-20 minutes to administer this test. High internal consistency was shown for both measures, with Cronbach alpha coefficients of .92 and .90 for the S-Anxiety scale, and .92 and .88 for the T-Anxiety scale. The median item-scale correlation coefficients were .60 for the S-Anxiety scale and .59 for the T-Anxiety Scale (Ramaniah et al., 1983). Correlations between this scale and other measures of trait-anxiety include the Taylor Manifest Anxiety Scale, IPAT Anxiety Scale, and Multiple Affect Adjective Check List. These correlations are .80,.75, and .52, respectively (Spielberger, 1983).

An additional anxiety measure utilized is the Beck Anxiety Inventory (BAI; Beck et al., 1988). Having found that previous anxiety measures were highly correlated with depression measures, the Beck Anxiety Inventory was designed as a discriminate measure of the severity of anxiety in adult individuals (Beck et al., 1988). A 21 item scale, subjects rate each question on a four-point scale from 0 (“not at all”) to 3 (“severely, I could barely stand it”), with the various items inquiring about subjective, somatic, or panic-related symptoms of anxiety. It is a relatively short measure, and can be completed in 5-10 minutes. Scoring can be figured by adding the various responses, highly yielding a total score ranging from 0 to 63. The Beck Anxiety Inventory was moderately correlated with other self-report anxiety scales (range .25 - .69; Osman et al.,

1997). Additionally, the BAI shows significant factorial validity (Osman et al., 1997), as well as high internal consistency (coefficient alpha = .92) (Beck et al., 1988). A subsample of patients (n=83) completed the BAI after 1 week, and the correlation between intake and 1-week BAI scores was .75 (Beck et al., 1988). The BAI discriminated anxious diagnostic groups (panic disorder, generalized anxiety disorder, etc.) from nonanxious diagnostic groups (major depression, dysthymic disorder, etc.). Convergent and discriminant validity was shown to significantly discriminate homogeneous and heterogeneous diagnostic groups (Beck et al., 1988).

Next, the Intolerance of Uncertainty Scale (IUS; Freeston et al., 1994) is a measure that was developed in order to determine one's reactions to and implications of being uncertain, and how uncertainty affects one's present responses and future planning (Freeston et al., 1994). The IUS has 27 items that are rated on a five point Likert scale ranging from "not at all characteristic of me" (1) to "entirely characteristic of me" (5). Originally written in French, the French version shows high internal consistency with an alpha coefficient of .91, with a good test-retest reliability of .78. Additionally, it showed both convergent and discriminant validity (Dugas et al., 1997; Freeston et al., 1994). Using an established translation method, the French IUS was translated to English (Vallerand, 1989). Thus, Buhr and Dugas (2002) embarked upon a validation study for the English IUS, testing 213 undergraduate participants. Four factors were identified in the English version: a. uncertainty leading to the inability to act, b. uncertainty is stressful, c. unexpected events are negative, and d. unexpected events should be avoided. The correlations of the above four factors ranged from .42 to .69 (Buhr & Dugas, 2002). All of the factors were highly correlated with total IUS score, ranging from .82 to .94.

Correlation coefficients between the IUS and other measures were calculated, with the highest correlation occurring with the PSWQ (Meyer et al., 1990), a measure of one's tendency towards excessive worry, ($r=0.60$, $p<0.001$). Significant partial correlations were also found between the IUS and the PSWQ, when controlling for depression (as measured by the BDI-II; Beck, Steer, & Brown, 1996) and anxiety (as measured by the BAI; Beck, Epstein, Brown, & Steer, 1988). Additionally, good test-retest reliability was ascertained. One limitation of the study was the overwhelming majority of females, with 213 female participants and only 62 males (Buhr & Dugas, 2002). However, gender was not found to be significantly correlated with the IUS (Robichaud & Dugas, 2000). Further, due to the majority of females who have MS, this skew does not seem to be of concern for my study.

In order to measure the couples' relationship, the Dyadic Adjustment Scale (DAS; Spanier, 1976) was administered. A 32-item Likert-scale form, the DAS was developed for married and cohabitating couples, using 2, 5, 6, and 7 point response formats, and composed of four subscales: Consensus, Satisfaction, Cohesion, and Affectional Expression. Scoring is conducted by summarizing all four scales, creating a global index (Spanier, 1988). With high internal consistency (.90), the DAS score also shows high test-retest reliability for married couples over a three week period, boasting a high stability consistency of .87 (Carey et al., 1993). Other studies showed test-retest reliability to be .96 in an eleven week period (Stein et al, 1982) and .48 over four years in heterosexual as well as homosexual couples (Kurdek, 1992). Partial correlations showed that reliability was not affected by age, number of children, education, relationship duration, or length of time between test and retest (Carey et al., 1993). Good construct

validity was also found, in its high correlation with other measures of marital quality (Crane et al., 1990) and in its differentiation between distressed and nondistressed married couples (Eddy et al., 1991). Although the test is most often scored globally, it is important to note that the subscales exhibit fair to excellent internal consistency ranging from .73 (Affectional Expression) to .94 (Dyadic Satisfaction).

In addition to hypothesis testing, two additional measures were administered as well. First, the Mishel Uncertainty in Illness Scale (MUIS; Mishel, 1981), measures a patient's degree of uncertainty regarding his/her illness. A 30 item Likert scale, includes the scales of: a. ambiguity, b. complexity, c. lack of information, and d. unpredictability (Mishel et al, 1984), that patients have about their illness. The scoring is direct, with high scores indicating high uncertainty levels, and low scores showing low uncertainty levels. MUIS was found to show validity in that it significantly discriminated between medical, surgical, and patient populations with the predicted outcome (Mishel, 1981). Administered to 259 hospital patients, and factor analyzed, construct validity of the scale was demonstrated by showing that the MUIS discriminates between treatment groups. This factor analysis was replicated in a population of 100 patients, with a "remarkably similar" factor loading (Mishel, 1981, p. 261). The replication study also showed significant correlation between the MUIS and stress, as evidenced by the Hospital Stress Events Scale (Volicer, 1977). Yet a third validation study was conducted in order to assessing the relationship of the MUIS to a lack of comprehension in patients, using the Comprehension Interview from the Recall Test (Cassileth, 1980), with the correlation of the two tests pointing in the predicted direction (Mishel, 1981). Testing of the model with hospitalized medical patients indicated support for further construct validity regarding the

relationship of uncertainty to stress (Mishel, 1984). Reliability estimates for the scale are .92, with a range between .71 for the smallest factor, and .91 for the largest. The total scale coefficient alpha was. 93, with a .89 coefficient alpha for the ambiguity scale, and a .82 coefficient alpha for the complexity subscale (Mishel, 1981).

Finally, in order to measure subjects' MS physical symptoms before and after the intervention, patients were given the MS-Related Symptom Checklist (MS-RS, Gulick, 1989). Patients rated frequency of 22 common MS-related symptoms on a six-point Likert scale of 0 to 5, ranging from "Never" to "Always." Higher scores thus indicated a higher prevalence of symptoms. Signs and symptoms contained within the five-factor solution compared favorably (73-89%) with signs and symptoms assigned to the neurological functional systems which are used clinically in classifying MS disease impairment. Internal consistency and initial construct validity were both demonstrated with theta reliability coefficients of .74 and .87 for the factors. .

Data Analysis

In order to test the study's hypotheses for the presence of a treatment effect, several types of analyses were performed:

Analysis One: Individual Intent to Treat Analysis (ITT)

Overall Individual Intent to Treat

Patients' and partners' difference scores (between pre and post intervention) were pooled together and analyzed using Hierarchical Linear Modeling (HLM). HLM accounts for the fact that patients and partners are nested within couples and are correlated with each other. This test is akin to a t-test in that it tests whether the mean gain is statistically

different from zero; however, t-tests assume independence of data, whereas HLM does not. This test measures whether overall a treatment effect is detected, regardless of patient or partner status.

Patient and Partner Intent to Treat

It is hypothesized that patients and partners may respond differently to the treatment. Therefore, separate analyses to test for a treatment effect were conducted for patients and partners. To conduct this test, a repeated measure ANOVA was utilized where the repeated measure evaluated pre and post intervention scores for patients and partners separately. This could detect if, for instance, there may not have been an overall treatment effect for patients and partners together, but patients as a group did experience treatment effect.

Analysis Two: Individual Treatment on Treated (TOT)

Self report data were collected regarding how often and for how long individuals were meditating at the end of the intervention. From these data, two categories of treatment were created: high meditation and low meditation. Those in the high meditation group reported meditating three or more times per week for fifteen or more minutes each time. Those in the low meditation group reported meditating less than three times per week and/or for less than fifteen minutes each time. Analyses were conducted to compare the high meditation treatment effect versus the low meditation treatment effect. It would be hypothesized that those in the high treatment would have larger gains.

Overall Individual Treatment On Treated

Like the overall Intent to Treat analysis, above, the overall Treatment On Treated analysis was conducted using HLM. For this analysis, a post test score was predicted by

an intercept (an overall mean), a pre-test score and an indicator of being in the high meditation group. The indicator was tested to see if there was a significant difference from zero. This tests if there was a difference between the high and low meditation treatment effect, while taking into account the couple correlation.

Patient and Partner Treatment On Treated

Like the patients and partners Intent To Treat anlysis above, the patient and partners' TOT was analyzed using a repeated measure ANOVA. In this case, a between measure indicating high vs. low meditators was added, for patients and partners separately. Tests were conducted to examine if the change from pre to post differed for each separate treatment group.

Couples' Analyses

Whereas the previous analyses focused on treatment effect on the individual level, even when accounting for couple correlation, this study is also interested in couple change as a whole. To analyze this, two couple measures were created: one of combined couple change, and one regarding couple similarity. The measure for combined couple change was simply the sum of a patient's and his or her partner's gain scores. The second measure of similarity compared the distance between a patient and his or her partner's pretest scores with the distance between their post-treatment scores. When difference in scores became smaller, this indicated that couple partners' scores were more similar to each other. Additionally, four treatment groups were created: couples in which both patients and partners were high meditators, couples in which only the patient was a high meditator, couples in which only the partner was a high meditator, and couples in which neither patient nor partner was a high meditator. It should be noted that in these analyses,

the couples are the units of analyses, and couples are independent of each other, thus precluding the need for HLM analysis.

Analysis Three: Couples' Intent To Treat

Couples combined scores and similarity scores were analyzed separately using one sample t-test. In this case, the t-test was used to evaluate whether the combined score or similarity score was significantly different from zero. An ANOVA could not be used here since only one score at a time was being tested. Additionally, since couple scores were already independent of each other, there was no need for an HLM analysis.

Analysis Four: Couples' Treatment On Treated

Couples' Combined Scores

In order to test if there were differences by treatment group for the couples' combined scores, a one-way ANOVA was conducted, using a between measure which accounted for each of the four treatment groups. This tested if the mean combined scores significantly differed among groups. For instance, this test could indicate whether couples who both meditated had higher combined scores than those in which neither meditated.

Couples' Similarity Scores

In order to test the change in couples' similarity scores between pre and post intervention, a repeated measures ANOVA was conducted where the repeated measure was the couples' pre and post intervention similarity scores. The between measure accounted for each of the four treatment groups. Additionally, post-hoc Tukey HSD tests were conducted to compare pairs of the four treatment groups to each other. For instance,

this test would indicate whether couples in which both partners meditated became closer together when compared to couples in which only one person meditated.

Analysis Five: Within Couple Pre-Test Comparison

In addition to the above tests, pre-test scores were compared within each couple, in order to determine a priori differences in couple partners. Using repeated measures ANOVA, patients' and partners' pre-intervention scores were compared. This could indicate, for example, whether, prior the intervention, patients or partners had higher anxiety levels.

Analyses One through Six were conducted for the following measures: Beck Anxiety Inventory, Dyadic Adjustment Scale (and its four subscales: Dyadic Consensus, Satisfaction, Affection, and Cohesion scales), State and Trait Anxiety Indexes, Intolerance of Uncertainty Scale, Mishel Uncertainty of Illness Scale, and Multiple Sclerosis Related Symptoms. Differences were considered statistically significant at a threshold of $p < .05$, with $p < .10$ indicating a non-significant statistical trend.

CHAPTER FOUR

Results

Descriptive Statistics

The treatment sample consisted of two treatment groups, T1 and T2. T1 and T2 differed in many regards, despite similar recruitment strategies (See Appendix C). In T1, there were twelve couples, with three couples dropping out. In T2, there were thirteen couples, with one couple dropping out. Drop outs all occurred early in the class, reportedly due to a combination of geographical difficulties and life stressors. T1 and T2 both had a similar average participant age, of 47 and 49, respectively. Wide ranges of income were reported for both groups. T1 consisted of 16 Caucasian-American participants and two mixed race couples, while T2 consisted of nine Caucasian couples, one mixed race couple with one Caucasian and one Latin-American participant, as well as one Indian-American, one Asian-American, and one African-American couple. The majority of patients were female. As to sexuality, in T1, there was one lesbian couple and in T2 there were three lesbian couples; all other couples were heterosexual (see Appendix C).

Hypothesis Testing

Hypothesis One: Anxiety

It was predicted that the MBSR intervention would reduce anxiety in the participating couples who had one partner with MS. State Trait Anxiety Index (STAI) and Beck Anxiety Scale (BAI) were utilized in order to assess participants' anxiety levels.

State Trait Anxiety Inventory Results

The STAI consists of two subscales, the State Anxiety Inventory (SAI) and the Trait Anxiety Inventory (TAI). For the SAI and the TAI, a positive mean difference indicates that the post test score was higher than the pretest score, showing an improvement in anxiety levels. The following set of analyses was designed to test the hypothesis that STAI test scores would improve with treatment, thus showing that the treatment would decrease state and trait anxiety.

I. STAI – State (SAI)

I. Analyses of Individuals

1A. Intent to Treat: Overall

The first analysis was implemented to test whether the treatment worked for all participants as a group, regardless of patient or partner status. To examine this, patients' and partners' difference scores (between pre and post intervention) were pooled together and analyzed. Hierarchical Linear Modeling (HLM) was used because it accounts for patient and partner couple correlations.

In this analysis, HLM showed no significant overall gains in participant SAI scores, indicating that there was no difference in state anxiety for the group post-treatment.

1B. Intent to Treat: Patient and Partner

While the state anxiety of the group as a whole did not appear to have been affected by treatment, the question arose as to whether patients and partners might have responded differently from each other. Thus, ANOVA was utilized to evaluate the repeated measure of partner and patient pre and post scores separately. This could detect if, for instance, there may not have been an overall treatment effect for patients and partners together (IA), but patients as a group did experience treatment effect (IB).

For the SAI, Analysis IB indicated a non-significant trend in state anxiety improvement of .239 for SAI patients ($F(1, 18) = 4.033$), $p = .06$). Thus, while no significant change in state anxiety was found in partners, at treatment's end patients did show a trend towards state anxiety improvement.

Individual Treatment on Treated (TOT)

A large part of the treatment consisted of doing "homework," a daily meditation practice. When evaluating whether the treatment had worked, the question came up as to whether there might be a difference between those who adhered to treatment outside of class and those who did not. In order to evaluate this, self report data were collected regarding how often and how long individuals were meditating at the end of the intervention. From these data, two categories of treatment were created: high meditation and low meditation groups. Those in the high meditation group reported meditating three or more times per week for fifteen or more minutes each time. Those in the low

meditation group reported meditating less than three times per week and/or for less than fifteen minutes each time. Analyses were conducted to compare the high meditation treatment effect versus the low meditation treatment effect. It was hypothesized that the "treatment" would have a greater effect on the "treated" group, the high meditation group that adhered to treatment and meditated regularly. Eight partners reported being high meditators, while eleven partners reported being low meditators. Ten patients reported being high meditators while nine patients reported being low meditators.

1C. Treatment on Treated: Overall

Analysis IC was conducted to test whether the amount of time participants spent mediating would affect levels of state anxiety, regardless of patient or partner status. As in Analysis IA, patients' and partners' difference scores (between pre and post intervention) were pooled together and analyzed using HLM.

No significant difference was found between high meditator and low meditator SAI scores, indicating that, when evaluating the entire treatment group, increased meditation did not affect state anxiety.

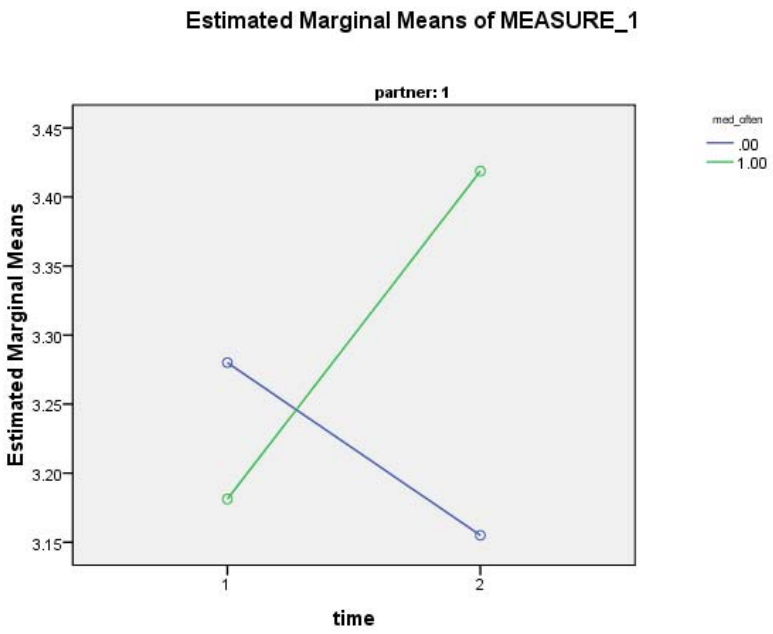
1D. Treatment on Treated: Patient and Partner

The next step was to evaluate whether patient meditators responded differently from partner meditators to the treatment. As in Analysis IB (above), ANOVA was utilized here as well to examine partner and patient scores separately.

Analysis ID results indicated no significant results for patients. However, for partners who meditated often, the slope of the change between pre- and post- intervention SAI scores showed a trend towards significant difference ($F\ 1, 16) = 3.47$, $p=.08$). The low-meditating group started with higher SAI pre-test scores than the high-meditating

group (3.28 vs. 3.15), but had lower SAI post-test scores (3.18), while the high-meditating group had higher post-test scores (3.41). Thus, high meditator partners showed a higher rate of change than low meditator partners.

Figure One



II. Couples' Analyses

While it was important to assess how the treatment affected state anxiety for individuals, it was also important to understand how the couple unit was affected as well. Did both patient and partner improve as a unit? Did they become more similar or dissimilar at treatment's end? To analyze this, two couple measures were created: one of combined couple change, and one regarding couple similarity. The measure for combined couple change was simply the sum of a patient's and his or her partner's gain scores. The second measure of similarity compared the distance between a patient and his or her partner's pretest scores with the distance between that same couple's post-treatment scores. Smaller difference scores would indicate that couple partners' scores became more similar to each other.

Analysis 1E. Couples' Intent to Treat

Couples' combined scores and similarity scores were analyzed separately using one sample t-test. In this case, the t-test was used to evaluate whether the combined score or similarity score was significantly different from zero. An ANOVA could not be used here since only one score at a time was being tested. Additionally, since couple scores were already independent of each change in couples' scores. other, there was no need for an HLM analysis.

This analysis revealed no significant results for the SAI. Thus, couples did not exhibit any significant changes in similarity or improvement when examined as a unit.

Analysis 1F. Couples' Treatment On Treated

As in the individual analyses, it was important to understand wheher adherence to treatment would affect the direction of couples' scores. Thus, four treatment groups were created: a) couples in which both patients and partners were high meditators, b) couples in which only the patient was a high meditator, c) couples in which only the partner was a high meditator, and d) couples in which neither patient nor partner was a high meditator.

IF1. Couples' Combined Scores

First, it was necessary to assess whether couple scores as a unit improved. In order to do this, a one-way ANOVA was conducted, using a between subjects measure that accounted for each of the four treatment groups. This tested whether the mean combined scores significantly differed among groups. For instance, this test could indicate whether couples who both meditated had higher combined scores than those in which neither meditated.

No significant change in combined couple scores was found for the SAI indicating that couples who meditated did not show a significant change in state anxiety.

IF2. Couples' Similarity Scores

In order to test the change in couples' similarity scores between pre and post intervention, a repeated measure ANOVA was conducted where the repeated measure was the couples' pre and post intervention similarity scores. The between measure accounted for each of the four treatment groups. Additionally, post-hoc Tukey HSD tests were conducted to compare pairs of the four treatment groups to each other. For instance, this test would indicate whether the scores of couples in which both partners meditated became closer together when compared to couples in which only one person meditated or to couples in which neither meditated.

No significant change in couple similarity scores was found for the SAI, indicating that couples' state anxiety levels did not become significantly more or less similar to each other post intervention.

IG. Pre-Test Score Comparison

Finally, in order to better understand the significance of post test score changes, it was important to evaluate whether there had been significant differences in patient and partner scores before they began treatment. For example, did patients begin with higher state anxiety scores than partners? For example, partners did not display much state anxiety from the beginning, they ma have experienced a ceiling effect. Thus, Analysis IG examined patient and partner pre-test scores to determine whether patients and partners began treatment with significant differences in scores.

SAI indicated that partners had higher pre-test scores than patients ($p = .021$), indicating that partners began treatment with significantly less anxiety than patients.

II. STAI – Trait (TAI)

IIA. Intent to Treat: Overall

As noted above in 1A, when examining TAI scores it was also important to test whether the treatment worked for all participants as a group, regardless of patient or partner status. In this analysis, HLM showed no significant overall gains in participant TAI scores, indicating that there was no difference in anxiety for the group post-treatment.

IIB. Intent to Treat: Patient and Partner

While the trait anxiety of the group as a whole did not appear to have been affected by treatment, it was important, as above (1B) to assess whether there was a difference between patients and partners in trait anxiety change. Once again, ANOVA was utilized to evaluate the repeated measure of partner and patient pre and post scores separately.

For the TAI, Analysis One indicated a significant improvement in trait anxiety of .294 for patients ($F (1, 17) = 12.636$, $p = .002$). Thus, while no significant change in trait anxiety was found in partners, at treatment's end patients did show significant trait anxiety improvement.

IIC. Treatment on Treated: Overall

Again, it was important to distinguish those who adhered to treatment from those who had not. First, the high and low meditators were examined as a group, regardless of patient or partner status. As in Analysis 1C, patients' and partners' difference scores (between pre and post intervention) were pooled together and analyzed using HLM.

No significant difference was found between high meditator and low meditator TAI scores, indicating that, when evaluating the entire treatment group, increased meditation did not affect trait anxiety.

IID. Treatment on Treated: Patient and Partner

Next, the question of whether patient meditators responded differently from partner meditators to the treatment was evaluated. ANOVA results indicated no significant difference in TAI scores of patient and partner low and high meditators.

IIE. Couples' Intent to Treat

As above, it was important to assess how couples' trait anxiety as a whole was affected, whether both couple members' scores improved or worsened, and whether couple members became less or more similar to each other at treatment's end. There were no significant changes in combined couple TAI scores, indicating that couples did not improve or worsen in trait anxiety as a unit. However, couples' patient and partner TAI scores did become significantly more similar to each other ($p = .002$) over the course of the intervention (see Appendix B). This indicates that patient and partner's trait anxiety levels became more similar after the intervention than they had been prior to treatment.

2F. Couples' Treatment On Treated

As in the individual analyses, it was important to understand whether adherence to treatment would affect the direction of couples' scores.

2F1. Couples' Combined Scores

No significant change in combined couple scores was found for the TAI indicating that couples who meditated more frequently did not show a significant change in trait anxiety.

2F2. Couples' Similarity Scores

No significant change in combined couple scores was found for the TAI, indicating that couples' trait anxiety levels did not become significantly more or less similar to each other post intervention.

2G. Pre-Test Score Comparison

When examining patient and partner pre-test scores, partners were found to have higher pre-test TAI scores than patients (p =.001).

III. Beck Anxiety Inventory (BAI) Results

The following set of analyses were designed to test the hypothesis that BAI test scores improved (i.e. were associated with lower BAI scores) for patients and partners over the course of the treatment.

IIIA. Intent to Treat: Overall

For the BAI, no significant change in anxiety levels was found in group participants as a whole.

IIIB. Intent to Treat: Patient and Partner

Patients and partners were each analyzed to examine whether there were different treatment effects for each group. For the BAI, no significant change in anxiety levels was found in patients or partners.

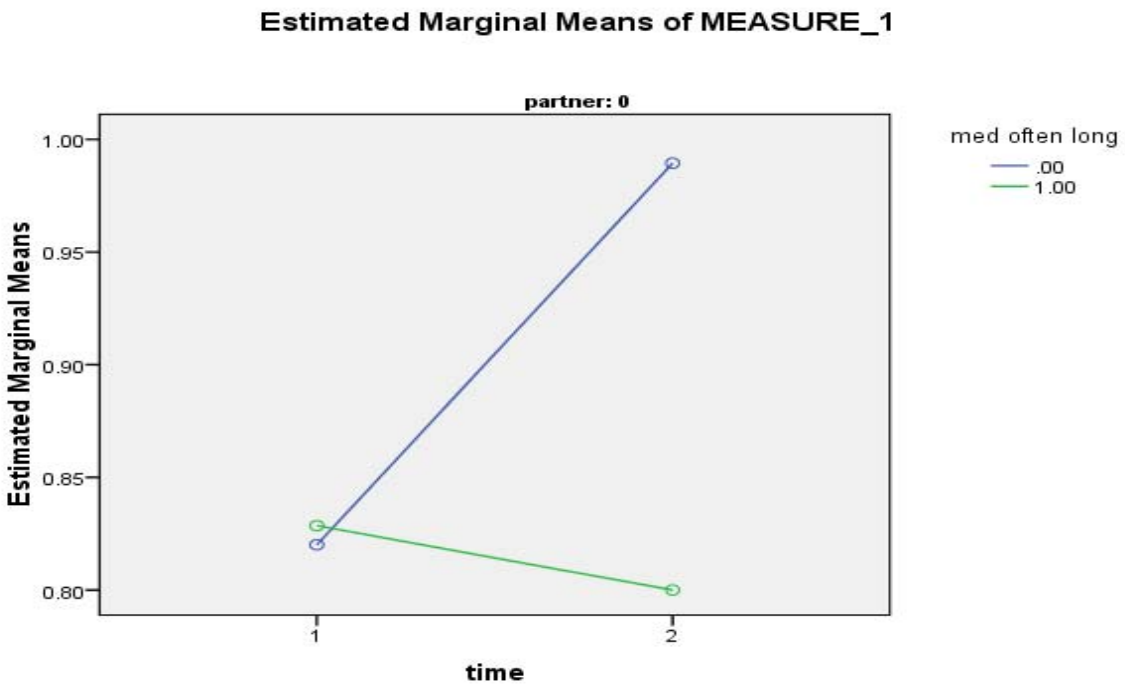
IIIC. Treatment on Treated: Overall

Again, it was important to discern those who adhered to treatment from those who had not. For the BAI, no significant change in anxiety levels was found in group participants as a whole.

IIID. Treatment on Treated: Patient and Partner

Next, low and high meditators were separated out by patient and partner status. BAI results indicated that for patients who meditated often, the slope of the change between pre and post- intervention scores showed a trend towards significant difference ($F(1, 17) = 3.32$, $p = .086$). While the low-meditating and high-meditating patient group started with similar BAI pre-test scores, after the intervention, the high meditator patients ended with lower BAI scores (from .820 to .989), indicating lower anxiety, while the low meditator patients ended with higher BAI scores (from .829 to .800), indicating higher post-treatment anxiety.

Figure Two: Patient BAI Results



IIIE. Couples' Intent to Treat

As above, it was important to assess how couples' trait anxiety was affected as a whole, whether both couple members' scores improved or worsened, and whether couple members became less or more similar to each other at treatment's end. The results of Analysis 2E indicated that no significant change in couples' BAI score similarity occurred. However, couples' combined BAI scores revealed a non-significant trend towards anxiety increase of .145 (t (16) =1.945, p=.07). Thus, according to BAI scores, couples may have actually increased their anxiety by treatment's end.

IIIF. Couples' Treatment On Treated

IIIF1. Couples' Combined Scores

No significant change in combined couple scores was found for the BAI indicating that couples who meditated more frequently did not show a significant change in anxiety.

IIIF2. Couples' Similarity Scores

When examining whether couples' scores became more or less similar, Analysis IIIF2 found significant differences between the treatment groups ($F(1, 3) = 3.6$, $p = .043$). Couples in which either patients or partners were high-meditators (but not both) began at comparable amounts of similarity in scores (around .80); however, at the end of the study those with a high-meditating partner decreased their similarity (to 1.10), whereas those with a high-meditating patient increased their similarity (to .36). Meanwhile, those couples in which both members were either high or low meditators did not experience significant changes in similarity. Thus, a high meditating patient led to increased couple similarity in BAI scores post-intervention, while a high meditating partner led to decreased couple BAI score similarity.

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IIIG. Pre-Test Score Comparison

When examining patient and partner pre-test BAI scores, patients had higher pre-test scores than partners, ($F(1, 16) = 12.22$, $p = .003$), indicating that patients began treatment with significantly more anxiety than partners.

Hypothesis Two: Uncertainty

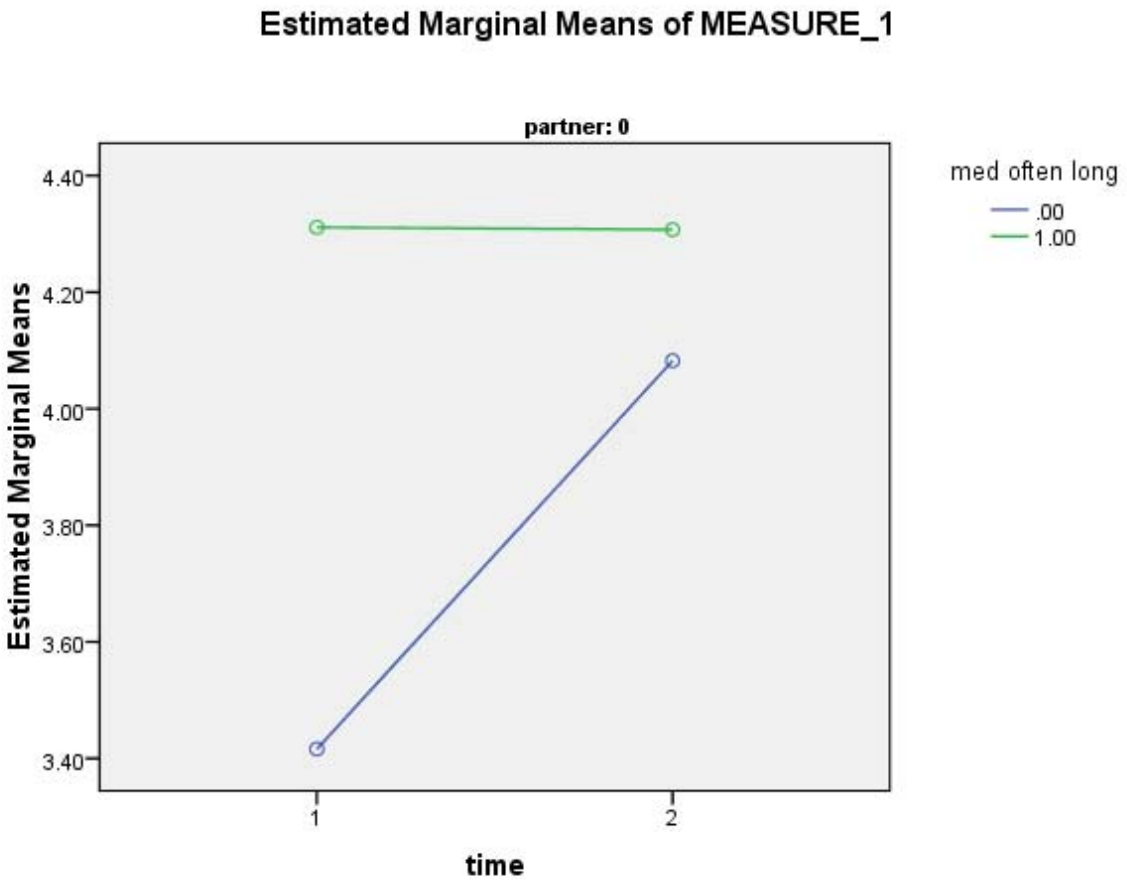
It was predicted that the MBSR intervention would increase participants' tolerance of uncertainty. In order to measure this, the Intolerance of Uncertainty Scale (IUS) was utilized. Additionally, the Mishel Uncertainty of Illness Scale (MUIS) was also employed to measure participants' perception of level of uncertainty in their illness.

IV. Intolerance of Uncertainty (IUS) Results

IVA. Intent to Treat: Overall

For all participants in the treatment, IUS scores increased between pre- and post-intervention by an average of .4016 ($t(16) = 2.719$, $p = .016$).

Figure Three: Intolerance of Uncertainty Overall Effect



IVB. Intent to Treat: Patient and Partner

Because it was already established that IUS had a significant overall effect for patients and partners, it was not necessary to run an analysis of patients and partners separately.

IVC. Treatment on Treated: Overall

Results revealed no significant difference between high and low meditators in uncertainty intolerance.

IVD. Treatment on Treated: Patient and Partner

For patients who meditated often, the slope of change between pre- and post-intervention IUS scores showed a significant difference ($F (1, 17) = 8.789$, $p = .009$). Surprisingly, the low-meditating patient group experienced an improvement in uncertainty tolerance (from 3.41 to 4.08), while the high-meditating group did not change (from 4.31 to 4.30).

IVE. Couples' Intent to Treat

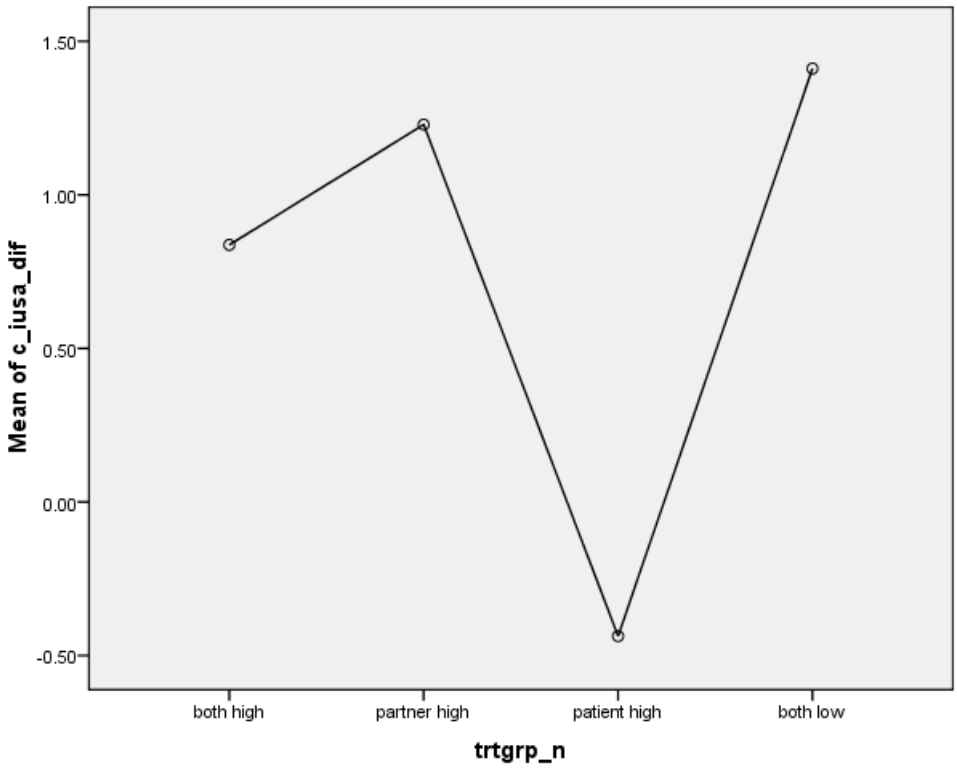
When examining overall increase and similarity change in couples' scores, results indicated that the combined IUS couple scores increased at a significant average rate of .74 ($t (18) = 2.768$), $p = .013$) (see Appendix One). This indicates that couples were better able to tolerate uncertainty as a unit at treatment's end.

IVF. Couples' Treatment On Treated

IVF1. Couples' Combined Scores

Results indicated significant differences in couples' IUS combined scores ($F (3, 18) = 3.6$, $p=.038$). Specifically, couples in which both members were in the low-meditation group experienced the largest increases in combined scores (mean 1.411), followed by couples in which only the partner was in the high-meditation group (mean 1.228), couples in which both members were high-meditators (mean .837), and couples in which only the patient was a high meditator (mean -.437) (see Appendix Two). Thus, couples who were both high meditators exhibited the least amount of increased uncertainty tolerance.

Figure Three: mean of IUS Couple High and Low Meditaors



IVF2. Couples' Similarity Scores

Couples' similarity scores were not affected by treatment. Thus, treatment did not lead couple members to become significantly more or less dissimilar.

IVG. Pre-Test Score Comparison

When examining patient and partner pre-test IUS scores, partners had higher pre-test IUS scores than patients ($p = .046$), indicating that partners began treatment with a higher level of uncertainty intolerance than patients.

V. MUIS Results

VA. Intent to Treat: Overall

For the BAI, no significant change in anxiety levels was found in group participants as a whole.

VB. Intent to Treat: Patient and Partner

When examining treatment effect on MUIS scores of patients and partners separately, patients showed a trend towards a significant increase of .184 ($F(1, 18) = 3.345$), $p = .084$). This indicates that at the end of the intervention patients perceived their illness as less uncertain.

VC. Treatment on Treated: Overall

Results revealed no significant difference between high and low meditators in perception of illness uncertainty.

VD. Treatment on Treated: Patient and Partner

Results revealed no significant difference between high and low meditators in uncertainty intolerance.

VE. Couples' Intent to Treat

When examining overall increase and similarity change in couples' scores, results indicated that couple MUIS scores trended towards becoming significantly closer ($F(1,18)=3.345$, $p=.084$) over the course of the intervention (i.e. reduced the gap by .168) (see Appendix A).

VF. Couples' Treatment On Treated

VF1. Couples' Combined Scores

When examining whether rates of meditation affected couples' overall scores, results revealed no significant change in couples' combined MUIS scores.

This result shows that there was no significant increase or decrease in couples' combined perception of illness uncertainty.

VF2. Couples' Similarity Scores

When examining whether rates of meditation affected couples' similarity scores, results revealed no significant increase or decrease in couples' MUIS score similarity. Thus, couples did not become more or less dissimilar in their perception of illness uncertainty.

VG. Pre-Test Score Comparison

Results indicated no significant difference in patient and partner pretest MUIS scores.

Hypothesis Three: Relationship

It was predicted that the MBSR intervention would lead to increased couple satisfaction. The Dyadic Adjustment Scale (DAS) was used to test this hypothesis. The DAS Global Scale is an additive scale, with scores going from 0 to 151, with higher scores indicating higher couple adjustment. Additionally, as noted above, the DAS is broken into four subscales: Dyadic Consensus (0 to 65 points), Satisfaction (0 to 50 points), Cohesion (0 to 24 points), and Affectional Expression (0 to 12 points).

VI. DAS Global Scale

No significant results were found in the DAS Global Scale.

VII. DAS Consensus and Affectional Expression Subscales

No significant results were found in the DAS Consensus or Affectional Expression subscales.

VIII. Dyadic Cohesion Subscale

VIIIB. Intent to Treat: Patient and Partner

When examining patients and partners separately, only partners show a significant increase of 1.526 in their Dyadic Cohesion score ($F(1, 18) = 5.661$, $p = .029$). Thus, partners perceived an improvement in Dyadic Cohesion post intervention.

VIIIA, VIIIC-F. Each of the other analyses indicated no significant differences in the DAS Cohesion Scale.

VIX. Dyadic Satisfaction Subscale

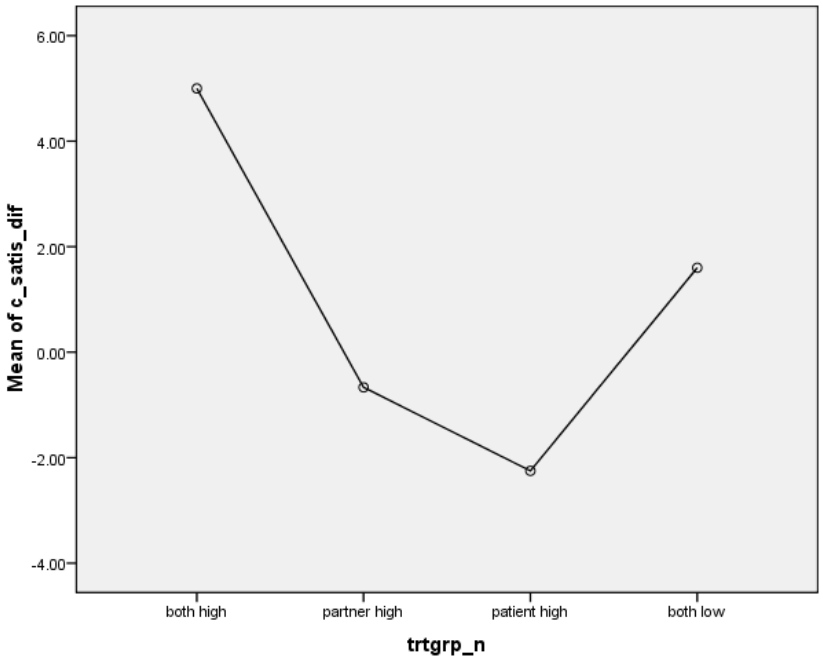
VIXA-VIXE. Analyses One through Three indicate no significant differences in the DAS Satisfaction Scale.

VF. Couples' Treatment On Treated

VF1. Couples' Combined Scores

When examining whether rates of meditation affected couples' overall scores, results revealed a trend towards significant differences in couple combined scores ($F (3, 16) = 2.8$, $p = .08$). Statistics indicated that those couples in which both members were high meditators experienced the largest gains (mean = 5.0), followed by those in which both were low meditators (mean = 1.6), those in which only partners were high-meditators (mean = -.667), and those in which only patients were high-meditators (mean -2.25) (See Appendix B). Thus, couples in which both partners meditated revealed the greatest improvement in satisfaction, whereas couples in which only one partner meditated were less satisfied at treatment's end than they had been before treatment.

Figure Four: Mean of Satisfaction Differences for High/Lo Meditators



VF2. Couples' Similarity Scores

When examining whether rates of meditation affected couples' similarity scores, results revealed that couples were no more or less similar in their DAS Satisfaction score post intervention.

VG. Pre-Test Score Comparison

When examining whether patients and partners began treatment with differences in their DAS Satisfaction scores, results indicated that partners had higher pre-test DAS Satisfaction scores than patients ($p = .005$). Thus, partners were significantly more satisfied in their relationship than patients pre-intervention.

Additional Analyses

Additional analyses were performed to examine change in MS symptoms as measured by the Multiple Sclerosis Related Symptom Inventory (MS-RS). No significant differences were found for this measure on any of the analyses.

Qualitative Results

A self-report course evaluation collected at the end of the treatment group provided additional data to consider.

Treatment Impact

When asked if the MBSR intervention provided participants with "something of lasting importance," 100% of participants responded that it had. Additionally, a scale of one to ten with ten being "very important" revealed an average of perceived importance of 8.31.

Relationship Communication

Of the 22 participating couples, 18 patients and 20 partners stated that they were better able to communicate with each other. As to talking about the illness, 18 patients and 19 partners felt they were better able to talk about their own illness, while 18 patients and 21 partners felt they were better able to talk about MS in general. Finally, 17 patients and 21 partners felt their relationship improved as a result of the treatment.

Results Summary

As can be seen from the above results, ANOVAs and Hierarchical Linear Modeling analyses were conducted on patients and partners of the treatment group, both as individuals and as nested couples. Additional analyses categorized participants into two groups: high meditators and low meditators in order to conduct Treatment on Treated

analyses. Finally, pre-tests of patients and partners were examined to check for pre-treatment differences among couple participants.

Three hypotheses were tested: a. whether treatment decreased anxiety, b. whether treatment decreased uncertainty intolerance, and c. whether treatment increased relationship satisfaction.

Hypothesis One

It was predicted that the MBSR intervention would reduce anxiety in the participating couples who had one partner with MS. State Trait Anxiety Index (STAI) and Beck Anxiety Scale (BAI) were utilized in order to assess participants' anxiety levels.

Hypothesis One results were mixed. STAI results indicated no overall treatment effect. However, when examining patients and partners separately, patients showed significant reduction in trait anxiety and a trend towards reduction in state anxiety. Additionally, partners who were high meditators exhibited a trend towards anxiety state improvement. Further, couple trait anxiety scores became significantly closer together at treatment's end. Although partners exhibited no significant increase in state or trait anxiety, pre-test results indicate that partners began treatment significantly less anxious than patients. Thus, there may have been a ceiling effect for partners.

BAI scores showed no significant improvement in anxiety. However, patients who were high meditators trended towards anxiety improvement while patients who were low meditators trended towards anxiety increase. Surprisingly, couple units trended

towards increased anxiety. Pre-test BAI scores revealed that patients began with higher anxiety than their partners. As a result, when the partner was a high meditator couples trended towards decreased similarity in BAI scores, while when the patient meditated couples trended towards increased similarity in BAI post-test scores.

Hypothesis Two: Uncertainty

It was predicted that the MBSR intervention would increase participants' tolerance of uncertainty. In order to measure this, the Intolerance of Uncertainty Scale (IUS) and the Mishel Uncertainty of Illness Scale (MUIS) were utilized.

Hypothesis Two results indicate a positive treatment effect of increased uncertainty tolerance, as measured by the IUS, for both patients and partners, as well as for couples. However, an additional puzzling finding is that, contrary to the hypothesis, low meditating patients improved most in uncertainty intolerance.

MUIS scores, measuring perception of illness uncertainty, did not indicate a treatment effect. However, when separating patients and partners, patients showed a trend towards an improvement, indicating that patients perceived their illness as less uncertain at treatment's end. Additionally, couples trended towards moving closer together in MUIS scores after the intervention.

Hypothesis Three: Relationship

It was predicted that the MBSR intervention would lead to increased couple satisfaction. The Dyadic Adjustment Scale (DAS) was used to test this hypothesis.

Hypothesis Three results indicated that no significant change occurred in the overall Dyadic Adjustment Scale. However, when examining DAS subscales, partners increased in Dyadic Cohesion scores. Further, couples in which both partners were high meditators experienced the highest gains in the Satisfaction Subscale. Further, couples in which only one partner was a high meditator became less satisfied in the relationship post treatment than they had been at treatment's beginning. While other subscales did not indicate patient and partner pretest differences, Satisfaction pretest scores indicated that patients began treatment significantly less satisfied in their relationships than their partners. Perhaps as high meditating patients benefited from treatment, their satisfaction improved, leading to greater satisfaction in both partners.

Conclusion

Three hypotheses were tested to evaluate whether an eight week MBSR was effective in improving: 1) anxiety, 2) uncertainty intolerance, and 3) relationship for couples where one member has Multiple Sclerosis. In short, the results found for each hypothesis follow:

1) Anxiety improvement was demonstrated in patients only, and not their partners. However, partners who meditated more frequently did have a higher rate of improvement in state anxiety.

2) Patients, partners and couple units significantly improved their uncertainty intolerance, while patients also trended towards perceiving their illness as less uncertain. Here, couples who meditated the least showed the highest improvement.

3) Couples did not experience significant relationship improvement. However, patients and partners who were high meditators did significantly increase their dyadic satisfaction.

CHAPTER FIVE

Discussion

The purpose of this study was to examine whether an eight week Mindfulness Based Stress Reduction (MBSR) treatment protocol would reduce anxiety and uncertainty and improve dyadic adjustment for couples with one partner diagnosed with Relapse-Remitting Multiple Sclerosis. In order to do this, two treatment groups were recruited. Each was given the same MBSR treatment protocol. Three hypotheses were tested to evaluate whether MBSR was effective in improving: 1) anxiety, 2) uncertainty intolerance, and 3) relationship for the couples.

As mentioned in the previous chapter, results indicated the following:

1) When all subjects were analyzed together, no general improvement in anxiety was found. However, when examining patients and partners individually, both high and low meditating patients and high meditating partners showed anxiety improvement.

2) Patients, partners and couple units significantly improved their uncertainty intolerance, and patients also trended towards perceiving their illness as less uncertain. Surprisingly, couples who meditated the least showed the highest improvement.

3) The Global scale of the Dyadic Adjustment Scale did not show improvement. However, two of four subscales did yield significant results. First, partners improved on the Dyadic Cohesion Subscale. Second, on the Dyadic Satisfaction Subscale, couples improved most when patient and partner both meditated frequently. Interestingly, couples also improved, though less so, when patient and partner were both low meditators. Couples did not improve when patient and partner differed in meditation level. Neither

patients nor partners improved on the other two subscales, the Consensus and Affectional Expression scales.

This chapter explores how the findings of this study are supported by existing literature and how they extend it. Where the findings in this study diverge from or add to existing literature, possible reasons and implications of these findings are explored. Case examples and theoretical explorations are utilized to shed light on the treatment itself and to understand what happened to the participants during the treatment to bring about change. Finally, study limitations and directions for future research are explored.

Discussion of Results

Anxiety

Anxiety and MBSR

STAI results showed that both low and high meditating patients who underwent the MBSR intervention showed a reduction in trait anxiety, as well as a trend towards state anxiety improvement. Partners who were high meditating also showed a trend towards state anxiety reduction. Additionally, couples' trait anxiety scores became more similar to each other at treatment's end. Finally, patient pretest scores showed that patients began treatment with significantly higher state and trait anxiety than partners.

Beck Anxiety Inventory (BAI) results suggested a non-significant trend of "dose" intervention for patients, suggesting that high meditators improved more than low meditators. Next, when measured as a couple, BAI couple scores became less similar for couples with a high meditating partner, whereas for couples with a high meditating patient, BAI couple scores became closer together. Surprisingly, a non-significant trend suggested an increase in couples' combined anxiety levels. Finally, as in the STAI

results, patients' pretest scores also showed significantly higher anxiety than partners' scores.

Understanding the Results

BAI vs. STAI

How can we understand the differences between BAI and STAI results? First, the BAI is more of a state assessment than a trait assessment, with a focus on symptoms of anxiety rather than anxiety emotions. In fact, upon examining the BAI more closely, it became apparent that, due to its somatic components, it may not have been the best measure for this patient population. Many of the anxiety indicators of the BAI could actually be physical symptoms of MS, such as "numbness or tingling," "feeling hot," "wobbliness in legs," "dizzy or lightheaded," etc. The STAI, on the other hand, measures the emotional state of anxiety without the somatic components, likely a better measure for this population. Thus, BAI patient data may not be accurate, as the somatic components may not be reflective of the patients' anxiety, but rather of their MS symptoms.

The BAI finding that couple scores became less similar with a high meditating partner and more similar with a high meditating patient may seem puzzling. However, since patients began with significantly higher anxiety than partners, couples with a high meditating patient found patient improved anxiety and partner stagnation, leading to more similar couple scores. Meanwhile, couples with a high meditating partner found either a general stagnation or partner improved anxiety and patient stagnation. Since patients began higher in anxiety than partners, this combination led to greater score discrepancy.

Patients and Partners

When examining the entire treatment population, it initially seemed there were no significant results. However, when examining patients and partners separately, patient anxiety levels improved, while partner anxiety remained the same. Why would this be?

First, in the current study, patients began treatment exhibiting significantly higher anxiety than partners. This discrepancy makes sense when thinking of the direct illness experience of the patient – the symptoms, the limitations, and the stressors that the patient must face directly, while the partner is only indirectly affected. Nevertheless, previous researchers differ as to whether MS patients and their partners exhibit equal amounts of distress. Northouse et al. (1995) found that patients and partners showed no significant difference in anxiety levels. Surprisingly, in a study of patients and relatives dealing with cancer (Harrison et al., 1995), relatives were shown to exhibit higher anxiety than patients. Rolland (1994a) underscores that in chronic illness, while "the immediacy of loss may be heightened for the ill partner… the well spouse faces many of the same dilemmas" (p. 290). However, as in this study, Pakenham (1998) found that MS patients exhibit greater distress than their partners.

Even if patients began at a higher anxiety level, is it not plausible that patients and partners could still improve at a similar rate? Previous MBSR studies exploring anxiety reduction (Kabat-Zinn et al., 1992, Shapiro et al., 1998) targeted high anxiety patients. Perhaps MBSR is more effective in reducing chronic anxiety in these populations. In this study, the partner group may have experienced a ceiling effect in anxiety improvement.

As to patients and partners exhibiting similar levels of anxiety at treatment's end, this is most likely due to the above pretest discrepancy. Partners began with significantly

less anxiety thus possibly creating a ”floor effect.” Meanwhile, patients who began with significantly higher anxiety were able to improve with the protocol. Ultimately, both patient and partner ended with more similar anxiety levels at treatment’s end.

Another possibility for anxiety difference between patients and partners may lie in John Rolland’s (2002) illness phase theory. Rolland explains that partners may experience different phases of illness at different times. A patient living with MS for three years may be well past the “Crisis” phase, a high anxiety initial phase in which a person is first hit with the reality of with his/her illness. Partners, however, may not have quite “graduated” from this phase or ever fully stepped into it. An MBSR intervention may thus facilitate partners’ coming to terms with the “crisis” of a patient’s diagnosis and its implications, perhaps catapulting the partner into the “crisis” stage.

While this may seemingly be initially detrimental for partners, as a couple it may help patients and partners cope more effectively with the illness in the long run. As Rando (2000) notes, many couples facing loss, including “ambiguous” (Boss, 2000) and “anticipatory loss” (Rando, 2000), may react by either distancing themselves from each other or becoming fused. Couples who are able to face these challenges “and use that consciousness in an empowering manner to live more fully” adapt best and experience least constraint on their relationship (Rolland, 1994b, p. 329). Although these benefits were not directly evaluated in the measures, the unfolding of awareness may be part of a longer journey for couples more deeply understanding the illness and its implications.

Anxiety and Post Course Evaluations

Schwartz and Kraft (1999) found that patients who viewed their partners as having more negative reactions to their disability exhibited poorer overall mental health.

In this study, post-course evaluations showed that after the treatment 41 of the 50 participants felt they were better able to talk about the patient's illness, and 21 of the 25 partners and 23 of the 25 patients felt they are better able to talk about MS in general. Open communication about the illness may have led patients to have felt more empathy from their partners. Thus, perhaps as a result of engaging in an intervention together, and opening dialogue about MS, patients perceived their partners' greater understanding and acceptance of their illness. Schwartz & Kraft (1999) also found that greater independence and self-sufficiency were associated with patients who exhibited better mental health and less perceived disability. Thus, it is also feasible that as patients were given tools to manage their anxiety, their overall sense of helplessness decreased, leading to a greater sense of self-efficacy and independence (Bandura, 1977, Kabat-Zinn, 2000).

Uncertainty

Treatment Effects: Intolerance of Uncertainty Scale (IUS)

In the current study, patients and partners experienced significant improvement in uncertainty tolerance. While this increase was also true for most couples as a unit, for those couples in which only the patient was a high meditator, the couple's combined IUS score decreased, indicating less uncertainty tolerance. Further, low meditating patients began with lower pre-test scores and increased their scores throughout the treatment, whereas high meditating patients began with higher uncertainty scores and maintained them throughout the course of treatment.

Past research on MS and uncertainty has focused on whether uncertainty exists (Noseworthy et al., 2000), measuring uncertainty (Mishel, 1981), comparisons within couples (Janssens, 2003b) uncertainty and negative emotional well being (Wineman et

al., 1990), greater mood disturbance (Wineman et al., 1994), and higher depression with a lower sense of meaningfulness (Wineman et al., 1990). Positive results of uncertainty intolerance alleviation in this study show that MBSR for couples can be a source of emotional support for partners facing MS.

Two puzzling questions remain. First, why would it be that low meditating patients improve in uncertainty tolerance, whereas high meditating patients do not? This may be due to a ceiling effect in improvement. Upon closer examination of the data, high meditating patients were found to have higher pretest IUS scores. Thus, it was more difficult for them to improve as much as the low meditating patients who began with lower IUS scores. Second, why would IUS scores increase for all couples except for ones in which only the patient was a high meditator, while the partner was a low meditator? This finding remains a puzzle. Further research is indicated in order to better understand the relationship between uncertainty tolerance and meditation levels.

Treatment Effects: Mishel Uncertainty of Illness Scale

Originally a baseline measure, the Mishel Uncertainty of Illness Scale (MUIS) was not intended to be a measure of change, in that it was assumed that the perception of illness in treatment participants would remain constant. Nevertheless, patients showed a trend towards improvement, while partners did not show any change. Patient and partner MUIS scores also became more similar to each other post-treatment.

This trend could be understood in several ways. First, although the intention of the protocol was to provide skills training, some basic psychoeducation about MS was provided in the initial session. Although this psychoeducation would most likely not have provided much new information, perhaps just hearing the information again in a non-

crisis state may have affected participants' perception of the illness. Second, in addition to information about the illness, education was also provided about the psychology of MS – the anxiety and uncertainty of MS, and how they affect both couple partners. It may be that just the act of naming and providing space for participant emotions could have created a change in illness understanding and perception.

Yet a third source of change could have been from meeting and spending time with other participants. A great majority of the participants stated that just being with other MS couples was a wholly new experience for them, and just about every couple expressed that being with other couples facing MS was truly a new and comforting experience. Participants often socialized before and after the group, sharing information about medications, exercise protocols, doctors, etc. Personal physical and psychological experiences of MS were often shared in class as well. Thus, it is certainly possible that these interactions could have also led to a more "certain" perception of the MS prognosis, despite the lack of change in medical answers related to disease severity and course.

Another possible component of the change could be an increase in self efficacy and self control that participants gained through the course, leading participants to view their illness as less uncertain. While their illness may not have changed, increased self control would enable them to have a stronger command of their psychological reactions.

Patients vs. Partners

Why would patients, but not partners, improve in perception of illness uncertainty, when both improved in uncertainty tolerance? Once again, partners may have experienced a ceiling effect in this measure. As noted above, patients began with significantly higher anxiety and uncertainty scores. Perhaps then, as patients' high

anxiety abated, and tolerance of uncertainty increased, they may have been better able to take in information about their illness that they may have been too scared and anxious to integrate in the past. Thus, even if no new information was presented to participants, they may have been better able to process and make sense of the full range of possibility for the illness, rather than feeling frozen in the angst of not knowing. They may have also been able to ask more questions, conduct more online research, etc., for as one's anxiety is lifted one is better able to problem solve, to ask more creative questions, and to concentrate and take in more information (Willoughby Britton, seminar, MBSR National Conference, 2008) .

Why Uncertainty? Understanding the Difficulty of Uncertainty in MS

Whereas medical intervention can provide medications or other suggestions that can treat the course of illness, there are still a myriad of unanswered questions for MS patients, varying from person to person or from case to case. While some MS patients may exhibit cognitive difficulties, others may struggle more with balance or vision disturbance, while some may slide into progressive form of the disease.

Indeed, while initially the very thought of the MS diagnosis could bring with it a whole host of dangerous and terrifying possibilities initiating anxiety and stress reactions, the MBSR intervention, which taught participants to slow down and focus on the moment, could have in and of itself pushed away the idea of what "could happen" in the future. In the present moment, there is far less uncertainty, as we are living it and facing it and dealing with right here, right now. The more participants were taught to redirect their attention away from worrying about the past and the future, towards the immediate present, the more they may have learned to cope with stressors of the moment.

Additionally, as previous research suggests, by learning a new set of coping skills and practices, these participants perhaps gained a newfound sense of self-efficacy (Bandura, 1977, Kabat-Zinn, 2000). This sense of self-efficacy would thus provide participants with a greater sense of control and autonomy, knowing that they do have the ability to manage their circumstances in the future, just as they are able to manage their stressors in the present. Thus, their ability to tolerate not knowing becomes less terrifying, and more palatable, and their confidence in their abilities and skills to handle future stressors most likely increased significantly, hence alleviating one piece of the uncertainty – the knowledge that they can handle the moments that come upon them.

Relationship

Treatment Effects: Dyadic Adjustment Scale

In order to assess whether there was change in the couple relationship after the intervention, the Dyadic Adjustment Scale (DAS) was administered (Spanier, 1976). While the Global Scale showed no change, two of the four subscales yielded interesting results. First, on the Dyadic Cohesion subscale partner cohesion scores significantly increased post-treatment. Additionally, on the Satisfaction scale, a non-significant trend indicated that when both couple members were high meditators, couple satisfaction increases. Also of note is that satisfaction increased when both individuals were low meditators as well, although significantly less. However, for couples where only one person was a high meditator couple satisfaction decreased.

DAS Global Scale

When examining the questions of the DAS more closely, it is important to note that the scale is in many ways a “trait” scale, in that most of the questions ask about past

events, with the first 15 questions asking about past topics of arguments. It would be unlikely for these to change in such a short time, especially when couples in the group had been together an average of twenty years. Nevertheless, in another study, Carmody's (2004) study on Mindfulness Based Relationship Enhancement (MBRE) utilized MBSR for couples, and did show relationship improvement. However, Carmody's study focused on "nondistressed" couples with an average of 11 years of marriage as opposed to the 20 + in this study; his study also did not target illness. Further, MBRE incorporated more couple interventions: partner yoga, couple meditations, communication skills, etc. It also utilized a different relationship scale, the Quality of Marriage Index (QMI; Norton, 1983), which was deemed equivalent to the DAS (Heyman et al, 1994).

DAS Subscales: Cohesion and Satisfaction

In the Dyadic Cohesion subscale partners showed significant improvement, although patients did not show any change. The subscale consisted of five questions, including: "Do you and your partner engage in outside interests together?" and "How often do you work together on a project?" Since this measure was administered before and after an "outside interest" in which the couples "worked together on a project" one way to understand partners' change is by their engagement in the MBSR intervention. However, since patients did not indicate change in this subscale, the result seems a bit more complex. Perhaps, since patients began treatment higher in anxiety, uncertainty, and relationship dissatisfaction, their focus in treatment was on getting better. Partners, meanwhile, who began treatment less distressed may have felt closer and more empathic to patients after learning more about MS and communicating with other couples about it. It may also be that patients' initial high anxiety levels may have originally initiated their

dissatisfaction; then, as they became less distressed and more similar in anxiety levels to their partners, couples may have felt more cohesive with the patients.

As to the Satisfaction Subscale, results show that when both couple members were high meditators there was a trend towards relationship satisfaction improvement. Interestingly, as noted above, low meditating couples also showed some improvement, albeit less. Couples with one high and one low meditator showed the lowest rate of improvement. Why would this be? It seems for couples aligned in their practice satisfaction increases; conversely, when only one partner undergoes treatment, couple members grow further apart. Herein lies the rationale for a couples' treatment rather than focusing on patient only -- if only the patient undergoes a successful psychological intervention, s/he may be in danger of confronting Rolland (2002) refers to as a situation in which the treatment was successful but the family unit "died." When both couple members undergo treatment together, they have an opportunity not only to improve their emotional distress individually, but also as a couple. According to this finding, if both couple members cannot undergo the intervention together, it may be better for the couple for neither partner to undergo treatment, rather than for only one to do so. This finding thus supports previous recommendations indicating a need for couples' based illness interventions (Rolland, 1985, Schwartz & Kraft, 1996, Pakenham, 1998).

Still, it is important to consider another possibility of couple discrepancy within couples with varying degrees of meditation. It is also possible that couples who meditate differently already differ in practice style or personality. These couples might have grown further apart when only one member practiced, leading to greater dissatisfaction in a partner continuing to take his/her polarized role (as in "the doer" vs. "the lazy one", etc.).

The Relationship – Qualitative Analyses

In course evaluations, the following questions addressed couples' relationship:

A. Do you feel you are better able to communicate with your partner?
B. Do you feel you are better able to discuss your/partner's illness with your partner?
C. Do you feel you are better able to discuss your/partner's illness in general?
D. Do you feel your relationship improved as a result of MBSR? If so, how?

Interestingly, while the couples did not improve on the DAS Global Scale, the answers to the above questions were overwhelmingly positive, with only five of the fifty individuals answering "No" to any of these questions. Three of these five noted that they had already communicated very well with their partner and thus no change had occurred. For those who had reported change, just about every couple replied to the open-ended query with an "increased ability to communicate" or "increased ability to understand each other."

MBSR: What Happened?

Below, I begin by outlining in detail what participants did in the MBSR course. I then provide case examples to illustrate how this treatment protocol specifically affected individuals and partners, so as to illustrate the process of change that occurs in an MBSR course. Most participants indicated that they felt a great deal of change has occurred, with 100% of participants responding that they "got something of lasting value or importance from taking the MBSR course." Further, when asked to rate the level of importance on a scale of 1-10, with "10" being most important, the average number reported was 8.5.

Breaking Down the Parts

MBSR is a "systematic patient-centered educational approach" which relies on intensive training in mindfulness meditation through a series of progressive exercises, both in and out of class (Kabat-Zinn, 1996). An eight-week, step-by-step intervention, the

protocol was developed by Kabat-Zinn (1990) at the Stress Reduction Clinic of the University of Massachusetts Medical Center and was immediately used in myriad research studies (Kabat-Zinn et al., 1992, 1996, 1997, 1998, 2001). The model has been used both in medical and non-medical settings internationally, including hospitals, schools, prisons, and in corporate arenas (Kabat-Zinn, 1996).

The Intervention

Although the MBSR protocol consists of a detailed, session-by-session recommendation, the Center for Mindfulness (CFM) at the University of Massachusetts Medical Center, where MBSR was created, reiterates the importance of "the moment" in the delivery of the protocol; thus, the protocol allows for flexibility based on the needs of the teacher and the group at the present time. The general outline of the program is:

10. Individual pre-program intake/assessment interviews (45-60 minutes) or group orientation sessions (120 minutes)
11. Eight weekly classes (2.0-2.5 hrs each)
12. An all day silent retreat during the sixth week of the program
13. Formal Mindfulness meditation methods:
    a. Body Scan Meditation: While the participant is lying down or in a comfortable position, a set of guided instructions leading subjects to notice each body part, is given either live or through audiotape or CD. Gentle Yoga: Meditation through movement; participants are encouraged to take notice of their body as it moves into various gentle postures.
    b. Sitting Meditation: Progressing from structured to unstructured, this meditation involves increasing lengths of time, in which subjects sit silently, in a still position, while adhering to the leader's instructions.
    c. Walking Meditation: a slow, mindful walking, in which subjects break down and notice each piece of their steps.
14. Informal Mindfulness Meditation methods:
    a. Awareness of Pleasant and Unpleasant Events: Participants take note of accompanying thoughts, feelings, and sensations, without acting on them.
    b. Awareness of Breathing: Participants encouraged to stop, take notice of their breath, noticing its quality and where they notice it in their body, etc.

   c. Awareness of Routine Activities such as eating, driving, walking: taking time to notice these events, doing them "mindfully" rather than rushing.
15. Daily home assignments: 45 minutes per day of formal mindfulness practice and 5-15 minutes of informal practice are assigned, 6 days a week, during the course.
16. Large and small group discussion, as well as couple discussion, is encouraged within the course, in order to explore the integration of course skills into daily life, exploring difficulties in completing homework assignments, questions, etc.
17. Psycho-education: The origin of stress in the body and the history of stress research, uncertainty and anxiety, and disease specifics are presented.

Class Outline Week to Week:

Class One	Welcome, Opening meditation: introduction of awareness of thoughts, emotions and sensations, Group discussion of meditation and MS, Review of guidelines for participation, Guided meditation: what has brought you here – what do you want?, Dyad discussion of meditation, Go-round with introductions, mindful eating raisin exercise, Body Scan, homework (listen to Bodyscan CD 1 x/day; do 9 dots exercise)
Class Two	Body scan, Standing yoga, Dyads/small groups discussion of homework, Large group discussion of homework, Introduction of awareness of breathing meditation, homework (body scan 1x/day, mindfulness and recording of pleasant events), Short meditation
Class Three	Sitting meditation, Small group discussion of homework, Large group discussion of homework, Floor yoga, Pleasant events meditation and discussion, homework (Alternating body scan with yoga, mindfulness and recording of unpleasant events)
Class Four	Standing yoga, Sitting meditation: awareness of breath and body, group discussion: Introduce stress reactivity: Negative and Positive coping, homework (Alternating body scan with yoga plus meditation; recording stressful communication)
Class Five	Standing yoga, Sitting meditation with awareness of breath, body, sounds, emotions and thoughts, choiceless awareness, midpoint of class meditation for recommitment, Dyads: discuss how program has been so far, Large group discussion of homework and course so far, Psychoeducation: ways of coping, reacting vs responding, Small groups: ways of coping with stress – how can reactions become responses?, homework (Alternating body scan with yoga plus meditation; mindful awareness of responding to challenges)
Class Six	Yoga, Sitting meditation, Group check-in, Large group: communication presentation and exercises, Dyads: Speaker-Listener technique, Dyadic Check in exercise ("I appreciate, need, offer"), Group sharing, Lovingkindness meditation homework (Alternating body scan with yoga plus meditation; once per week check-in)
Half-Day	Instructions for silence, Sitting meditation: awareness of breathing, Yoga, Body scan, Walking meditation, Lovingkindness meditation, silent lunch, Dyads, closing ceremony
Class Seven	Yoga, Sitting meditation, group discussion: half-day intensive, discussion of obstacles / aids to mindfulness, Short meditation, homework (self-directed practice, no tapes)
Class Nine	Body scan, Yoga, Sitting meditation, Dyads: how was course for you?, Large group sharing, Last meditation, wrap-up, fill out post-course measures

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Couple A: Fern and George: A Couple in Turmoil

Fern, 61, who had recently signed up for the MBSR class with her husband George, 67, called a few weeks before the class, explaining that she was having a difficult time in her relationship. According to Fern, her husband, George, who has MS, was exhibiting cognitive deterioration, though he and his doctors denied this. She and George had been married 17 years, and George was diagnosed with MS during their first year of marriage. His illness eventually left him unable to work and the couple, whose income dropped to around $50,000, was experiencing financial problems. “To be honest,” Fern told me over the phone, “if it wasn’t for our financial problems, we probably would no longer be married. Our relationship is pretty much dead, but we just can’t afford to get divorced.” I encouraged them to enroll in the course, at least to abate her burden and her stress level, as well as to “improve our ability to cohabitate better.”

Fern’s frustration with George immediately became apparent to class members. She was critical of him and openly expressed her frustrations with his cognitive difficulties. He appeared accustomed to these kinds of remarks, though her criticism seemed to make others slightly uncomfortable. She seemed very anxious and also very ready to take on a new intervention.

As the class took hold, both members of the couple seemed to respond well to the interventions. However, it is interesting to note that Fern was a high meditator while George was a low meditator; in this case this discrepancy seemed indicative of other divergent patterns in the relationship – the same differences that led to general relationship distress. It also seemed to point to the MS cognitive symptoms of which George seemed unaware and by which Fern seemed very burdened. While George often

forgot to do his homework, Fern came to class gushing at how much more relaxed she was feeling, and how the exercises really seemed to help.

While the couple did not shift from being on the brink of divorce to honeymoon love, it is notable that in her post-course measures, Fern moved on the DAS from "extremely unhappy" in the relationship to "fairly happy" and from "It would be nice if my relationship succeeds but I can't do much more than I am doing now to help it succeed" to "I want very much for my relationship to succeed and will do my fair share to see that it does." Her harsh criticism and visible anxiety really seemed to lift, and after guided meditations and yoga sessions, she seemed to leave class as if she had just been to a spa. After answering that she felt her relationship improved with mindfulness training, Fern noted that "I am trying to be more compassionate" and "I am trying to let more things roll off my back and not react so strongly to them."

George, in turn, also seemed to react well to the course. On the DAS, he moved from "I want very much for my relationship to succeed and will do my fair share to see that it does" to "I want very much for my relationship to succeed and will do all I can to see that it does." He also noted that his relationship improved because "I now feel I have the tools I need." The couple seemed friendlier to each other as the course progressed, and they even shared some intimate moments during a few of the couple exercises.

It seems that in this case, despite the couple coming in on the brink of divorce, and despite the discrepancy in meditation levels, the individuals of this couple improved markedly enough that the relationship was able to marginally improve. It also seems that the discrepancy of meditation levels in this couple pointed more towards pre-course differences and MS related forgetfulness on the part of the patient than it did to reactions

to the course intervention itself. Interestingly, despite Fern's visual agitation, and George's seeming lack of agitation, George did report higher anxiety at the treatment's beginning. Additionally, Fern's trait anxiety did not show nearly as much distress as her state form.

Couple B: Marge and Patrick: Supporting Each Other Through Illness

When Marge, age 63, first called to inquire about the MBSR course, she was interested primarily because a friend of hers had taken an MBSR class and had recommended it. She was, however, concerned. She and her husband, Patrick, 66, were prominent members of the community and even served on the board of several psychological organizations. She was diagnosed with MS at the age of 49, and as she explained, "Nobody knows I have MS and I would want to make sure to keep it that way." She and her husband, Patrick, both Caucasian, had been married 40 years, with an income of over $100,000. They both reported a "very happy" relationship. I explained the confidentiality of both the study and the clinical setting of the class, and explained that it would be explicitly gone over during the course. Marge seemed skeptical about the course in general, and I had a feeling that she was not so sure about the course (or me) as the class began. Nevertheless, she and Patrick attended regularly and seemed to especially enjoy participating and speaking with other couples who had MS, perhaps partially because she had been so "closeted" in her illness. They spoke about the relaxation they obtained from mindfulness practice, and seemed to especially enjoy practicing at home.

In the MBSR curriculum, Class Six is devoted to interpersonal communication. In the MBSR for Couples with MS adaptation, we focused Class Six primarily on couple

communication. As noted above, this session incorporates Speaker/Listener Technique and other methods for expressing oneself and being heard by one's partner. This particular evening, Marge arrived shaken. Due to her MS symptom of dizziness, she had fallen in the lobby. Apparently, her upset was only partially due to the fall. What most bothered her was her husband's lack of compassion for her plight. Having suffered a stroke which left him partially paralyzed, his way of trying to calm her was to say: "This is nothing -- look at all that I struggle with." Needless to say, this did not calm Marge; rather, it created the opposite effect of leading her to feel alone and invalidated.

When Marge shared this with the class, many patients reiterated that it was also difficult for them to express when they needed help from their partner and when they preferred to be left alone. Partners, in turn, expressed their frustration in not knowing when to help or what to do. In general, it seemed that this was a "hot topic" for many couples, and yet something they rarely discussed, as when things were going well, and the patient was in remission, the topic did not come up, and when the patient was relapsing, s/he was already in the throes of an attack.

The timing for this discussion turned out to be quite perfect as moved into the Speaker/Listener technique. During the exercise, Marge expressed to Patrick how invalidated she felt when he focused on his physical problems rather than hers. He, in turn, expressed that he had simply been trying to help. Some tears later, the couple eventually heard each other and ended the exercise hugging and holding hands.

By the course's end, Patrick noted that he gained much from the course, and felt he had "greater psychological awareness and greater ability to communicate with my wife about MS issues." He also noted that, "after our half-day silent retreat I took my

blood pressure. A chronic sufferer of high blood pressure, at 126/78 it was at the lowest I can ever recall. That is what I call real useful." Marge added that "I have incorporated meditation into my life. It has given me peace and focus." Additionally, she noted, "I have become more aware of any negative pessimistic thoughts and have tried to dispel these with mindfulness. This is hard for me, but I am more observant of any negativity that might make me depressed." Finally: "as a couple, we listen to each other in amore mindful way" and that the class "has helped me come out of the closet about my MS**."**

This example shows how some of the couple communication exercises, coupled with the relaxation exercises, allowed couples to shift together into creating a more understanding and mutually supportive space for illness communication. Data indicates that in this couple Marge was a high meditator while Paul was not. Also, Marge began with significant anxiety, which seemed to marginally improve at treatment's end, Paul reported no anxiety at all, illustrating a ceiling effect regarding change.

Couple C: John and Carol: Moving Past Perceived Limitations

John and Carol, a Caucausian American couple, ages 62 and 61 respectively, had been married 37 years. Carol was diagnosed with MS 14 years ago. It was John who first signed up for the course, eager to take a couple class devoted to yoga and meditation. Carol, on the other hand, was more skeptical, and remained quiet for much of the course. When the yoga exercises were first introduced (week 3) I received the following email:

> Hello!
>
> Carol is experiencing some problems via the yoga portion. I will make her take it real easy. She had severe back surgery a year ago March for a cyst and broken vertebrae after a bad fall at work. Workman's comp has been very unfair about the entire situation to her. Have a nice weekend.
>
> Later,

John & Carol

I called John and Carol and suggested that they go over the set with her physical therapist, in order to ascertain which elements of the set could work for her, and which need to be modified or just eliminated. Of course, if she felt that all of it was out of her reach, she could also do a sitting meditation instead.

One evening after class, near the end of the course, Carol came up to me very excitedly. She told me that at first she was sure she could not do the yoga. After our initial conversation, she tried a little bit and found, to her surprise, that she was able to do many of the gentle postures. The sense of empowerment that she felt from this discovery led her to wish to explore other yoga options as well, and she asked for yoga class referrals so she could continue her yoga study. On the final day of class, when people went around the room to share something they were grateful for, she proudly announced: "I can do yoga!" In her program evaluation she noted: "I am more mindful of everything I do, including my relationships. The course helped me to understand not only my feelings better, but others' as well."

After the day long course, I received the following email from John:

Hello Vered!

A quick thanks for all you have done so far in your program with us. Believe it or not, I never was that quiet since I can remember. It made my mind wander a lot less in the long run as far as I can say too. It was great hearing Carol come around and finally realizing the value in all you are trying to do as well with the yoga. (She has no idea I am writing this so it's a secret too -- lol.) I really enjoy the meditation a lot as well.

See You,
John

One element of note in this couple is that, as the general results show, this couple did not exhibit relationship improvement as measured by the DAS. To my surprise, their DAS scores showed they both began and end the treatment "extremely unhappy" in the relationship. Nevertheless, both couple members independently wrote in the course evaluation that they ended the course "more mindful of myself" and "more mindful of my partner/relationship." Further, both couples began similarly moderately anxious. They also both meditated frequently, though for short periods of time. It is thus unclear what future implications this newfound "mindfulness" would have on their future.

MBSR and Psychotherapeutic Theory in Context

Mindful Observing Leading to Change

As the examples above show, one of the primary changes occurring from the MBSR intervention was an expanded capacity to sit with one's emotions, prior to responding automatically. This spaciousness, practiced in the meditation exercises, seemed to pervade not only the exercises, but also participants' relationships to themselves as well as to others. It is this observing that led Marge to note that: "I am more observant of any negativity that might make me depressed" or Sarah to note that "I am more aware of my angry thoughts and am able to calm them down" and that "I have better awareness of my irritable feelings towards people I love."

Previous mindfulness researchers point to the power of mindfulness to change deep seated patterns merely through observation. As Segal et al. (2002) note, rather than attempting to ignore, repress or avoid unwanted thoughts, meditators were encouraged to welcome and allow these thoughts in. It was through sitting with these previously taboo thoughts and feelings that meditators could most effectively move through them. This

solitary act not only induced healing, but could also provide an empowering relationship of responsibility between the patient and his or her difficulties. Rather than trying to "do" something to "fix" difficult thought patterns, meditators are encouraged to "be" with these thoughts and feelings, and to explore them with a sense of curiosity and wonder, no matter how difficult they may be. It is through this neutral lens of the observer that one can discover patterns of behavior in a non-judgmental way, allowing for a person to choose change if s/he wishes, rather than to remain stuck in unconscious behavior loops.

This distinction between "reacting" and "responding" is a key tenet of Mindfulness Based Stress Reduction. As Jon Kabat-Zinn notes, when one becomes overwhelmed by external or internal stimuli one tends to go into "automatic pilot," with one's sympathetic nervous system going into overdrive. Rather, Kabat-Zinn suggests, we can train our bodies and our minds to STOP (Stop, Take a Deep Breath, Observe and describe our surroundings, sensations, emotions, and then Proceed). When we engage in such an activity of awareness, we stop the process of automatic pilot, and invite ourselves to "respond" in a more thoughtful, aware, and ultimately, secure, manner. Mindfulness "allows us to be more fully present, open, and capable of responding – like the 'good enough' parent" (Wallin, 2007, p.7), allowing ourselves to attune to ourselves.

Ultimately, by learning to disengage from reacting to negative thoughts and to see these thoughts as separate from their "selves," patients strengthen their observational skills. In a cyclical depression for example, when a meditator is faced with the incipient stages of a depressive relapse, s/he can respond more skillfully to the negative emotions rather than falling into an old emotional and behavioral pattern. Researchers on mindfulness and depression (Segal et al., 2002) report that participants of MBCT

(Mindfulness Based Cognitive Therapy) were significantly less likely to become depressed again in the year following their participation. Thus, by the very act of creating space and neutral observation within one's thoughts, meditators have the space in which to restructure their way of encountering the world. As Epstein puts it,

> The most revealing thing about a first meditation retreat (after seeing how out of control our minds are) is how the experience of pain gives way to one of peacefulness if it is consistently and dispassionately attended to for a sufficient time. Once the reactions to the pain – the horror, outrage, fear, tension, and so on – are separated out from the pure sensation, the sensation at some point will stop hurting (Epstein, 1995, p. 118).

While Epstein is most likely referring to emotional pain in this excerpt, it is here that we can also understand another participant, Gloria, who revels at the end of the daylong retreat that "the (physical) pain is gone!" after she engages in a series of mindfulness observatory exercises (although not a permanent change). Here also we can better understand the patients' reduction in anxiety as well as participants' overall increased uncertainty tolerance. As the bodily sensations of anxiety become separate from one's reactions to them, mental anguish can be alleviated.

Mindfulness and Increased Mentalization

As one can see from the case examples, one of the recurring gains noted by participants is increased understanding and patience with one's partner, as well as with oneself. This expanded understanding of the other, or the increased ability to "mentalize" is understood by attachment theory as a quality associated with secure attachment. Thus, according to attachment theory, the more insecurely attached individual may tend towards minimization, denial or overwhelm when faced with anxiety inducing stimuli, while the more securely attached individual ultimately learns to step back, mentalize, and

make more informed, thought out, and less automatic decisions. Thus, mindfulness can teach skills for becoming more securely attached within oneself. Wallin (2007) notes that

> Like a secure attachment relationship, mindfulness can temper the acute reactivity of the amygdala and sympathetic nervous system that marks the emotion processes of insecurely attached individuals – especially those who might be described as preoccupied or unresolved (Wallin, 2007, p. 162).

By "loosening the grip of the internal and external circumstances in which we find ourselves doubly embedded" (Wallin, 2007, p. 308), one develops a greater capacity "to freely feel, reflect, and love" (Wallin, 2007, p. 166). Ultimately, Wallin (2007) describes a "mutually supportive" relationship between mindfulness and mentalization (p. 166), one in which mentalization creates a safer, more accessible space for mindfulness, while mindfulness increases and deepens one's ability to develop empathy and trust:

> (Mindfulness) contributes to the regulation of difficult emotions. It also tends to deautomatize habitual patterns of response…. This identification with awareness – ultimately an experience of selflessness that lessens the need to protect the (personal) self – can strengthen our sense of an internalized secure base. Finally, mindfulness quiets the mind. Lowering the volume of mental static, it heightens our receptivity to signals from every domain of the self. Experiences of the mindful self are thus not only integrated but also integrating: They foster adaptive connections between different aspects of the self and between the self and others. (Wallin, 2007, p. 68)

In this way, mindfulness creates an improved capacity in the individual for relationship to the self, external events, and others. Here, we can follow Fern's alleviation of anxiety, leading to a reduction in criticism of her mate, and finally to a greater willingness to make the relationship work. Here also we can see Patrick's newfound understanding of Marge's struggle with MS, leading Marge to feel more comfortable accepting her illness, and ultimately feeling ready to "come out of the closet" about having MS.

Can Mindfulness and Psychotherapy Work Together?

As noted above, meditation seems to open one to new experience of oneself and others, as well as opens one to resetting new patterns. As Epstein puts it, “We are faced here with our first conundrum: Meditation, it seems can bestow the kind of ego strength necessary for a successful psychotherapy, but it cannot do the psychotherapy by itself” (p. 135). Epstein thus strongly suggests that not only does psychotherapy provide a nice complement to meditation, but that, especially in the West, where society does not support the meditative experience, psychotherapy for the meditator may often be indicated in order to integrate some of the new observations collected within meditation. Indeed, in a German study of MBSR for participants with chronic physical, psychological and psychosomatic illnesses, psychotherapy was found to have complementary positive effects (Majumdar et al., 2002).

Indeed, in course evaluations, several participants answered “How could the course be improved?” with their desire to further integrate the mindfulness exercises into daily life. Even though class discussion was often centered around this topic, allowing for a space to discuss challenges and questions, it does seem that some participants craved a therapeutic space for meaningful exploration of their experience.

Epstein’s ideas of the importance of psychotherapy as a complement to meditation are echoed by several Buddhist masters. Engler (1986) presents a case in which a young woman who suffers from anorexia, anxiety, insomnia and agitation approaches her master to learn meditation. The master spent weeks listening to her complaints. It was only after a few weeks that he began to teach her Vipassana. Within a few months, the woman was free of anorexia and insomnia and found herself more

satisfied with her interpersonal relationships. When the master was asked why he did not teach the young woman meditation right away his reply was “too much pain.” As Engler (1981) writes,

> You have to be somebody before you can be nobody…. Both a sense of self and a sense of no-self, in that order, are necessary to realize that state of optimal psychological well-being that Freud once described as an “ideal fiction” and the Buddha long before described as “the end of suffering.”

Indeed, it is important to note that while meditation did seem to alleviate anxiety for patients, it may also have opened up a whole new world of questions and concerns, both related to the individual as well as to one’s relationship. There may indeed have been important times of withdrawal during this process, leading perhaps to a decrease of affection, or a decrease of sharing, etc. Additionally, some individuals, as well as some couples, may have distinctly benefitted from couple or individual psychotherapy as an adjunct to the mindfulness work, as suggested above. It may be that therapeutic work would have been beneficial during the course, or perhaps better suited after the course to try to incorporate some of the changes made within the self as well as within the family system. In short, meditation provides an important rung in the ladder, but psychotherapy as well as medical intervention for the MS can be important adjuncts that can work to solidify the meditation base, especially in those who are most in need of further support.

Psychotherapy can also benefit from mindfulness. Although psychoanalysis can provide a window into one’s innermost feelings and wishes, on its own it may not lead to the depth of change that meditation can allow. As Epstein (1995) writes,

> …as every veteran of psychotherapy can attest, analysis can easily give understanding without relief. Meditation offers a method of recycling psychic pain, bringing about the very relief that is otherwise so elusive (p.127).

Segal et al. (2002) draw a similar conclusion with Cognitive Behavioral Therapy, noting that “fixing it’ is not always the best solution – sometimes it is better for the patient him/herself to observe and refine one’s behavior on one’s own. This sense of responsibility and self efficacy that mindfulness can cultivate (Bandura, 1977, Kabat-Zinn, 2000), whether it be in a context of an eight week protocol such as MBSR, or within a therapy office. Thus, theory and practice of mindfulness can be integrated into therapy as well, for both individual and couple work.

The Mindfulness Instructor: Teacher or Therapist?

Above, the self is described as an attuned other during meditation. However, the mindfulness teacher provides an important secure base as well. As expressed in attachment theory, an important tenet is the sense of ‘passing along’ the therapists’ secure acceptance and attachment to the patient who may have not experienced such an attachment relationship before. Just as a mother communicates a sense of security to her child – simply by being present “with” the person before her, a teacher provides a space of holding during the meditations by being “with” the person while s/he explores one’s inner sensations, emotions and reactions. This sense of “attunement” provides a nonverbal space in which patient and therapist, or mother and child, can share a sense of “being” with each other, a sense of common space. So too, if a therapist is able to provide a mindful, attuned stance to the patient, the patient can feel “held” by this security, and find him/herself better able to become “disembedded” and to mentalize more freely:

> The therapist’s mindful stance may have a ‘contagious’ quality – kindling the patient’s own experience of mindfulness very much as expressions of the therapist’s reflective stance help to kindle the patient’s ability to mentalize (Wallin, 2007, p. 7).

The importance of the therapist's attunement cannot be overemphasized in mindfulness theory and practice. It is common knowledge among meditators that the meditation teacher must meditate; teaching meditation simply doesn't work otherwise. When developing MBCT, Segal et al. (2002) found themselves unable to teach mindfulness simply as a skill, for a vital part of learning mindfulness meditation is through the instructor's "embodiment of mindfulness in interactions with the class" (p. 56). Without the instructors' ability to be mindful, as well as his/her ability to attune to participants, the "skills" of mindfulness fell flat. As Wallin (2007) explains,

> …mindfulness can be 'catching.' In the presence of another who is calm and accepting, it is easier to find calmness and a modicum of self-acceptance in ourselves. When as therapists we can be mindful, we often find the patient meeting us on common ground. All that can occur implicitly. We can also explicitly invite patients' mindfulness…. Whenever we direct attention neither to what has happened nor to what is going to happen, but, rather, to what is happening, we create opportunities for our patients to be mindful. And every time they are enabled to 'inhabit' the present moment with awareness and acceptance they strengthen their capacity for mindfulness' (p. 312).

Thus, the better a therapist or meditation instructor is able to attune to the patient or student, the more s/he creates a 'holding space' for the participant to explore his/her experience in a safe environment, knowing that the 'secure base' is intact, allowing exploration to be vast, while the sense of 'home' remains protected.

Indeed, in post-course evaluations for this study, many participants mentioned that the instructor's "compassion," "gentleness," "calm" were all important assets to the class. The instructor's openness and sense of acceptance seemed to provide participants with the holding space they needed to bring these same qualities to themselves.

Another Source of Attunement: The Couple Partner

As described above, mindfulness teaches openness and non-attachment, within the context of an accepting instructor, who is both attuned with class participants, and with him/herself. In this study, participants also experienced another piece of the puzzle – they also had their partners present, learning and practicing these skills as well. In class exit forms, almost every participant noted an increased ability to sit with the illness and its uncertainty; they also noted a more "mindful," "less reactive" ability to be with their partners around the illness, including more comfort in communicating about the illness with their partners, and more ability to accept the unknown. Many also wrote that they were now better able to bring compassion and mindfulness to themselves and to their partners. In this way, the skills and experiences that were developed in the mindfulness intervention helped participants become less "embedded" in their reactions, creating more space for tolerance of the moment, as well as for acceptance of their partners.

At the same time, it is important to note that just as some experienced a sense of holding and security from their partners, there were also participants who did not experience this during the class. It is even plausible that the lonely nature of the meditative exercises may have served to alienate some participants from their partners, causing a rift in the relationship – at least temporarily. While the course was taught as a couple intervention, it is important to note the existential nature of meditation, leading to self-empowerment, but perhaps not always to couple unification – at least not initially.

Mindfulness for MS: Why this population?

Ultimately, the question comes down to why MBSR would be particularly helpful to this group of people – couples dealing with Relapse-Remitting MS. As noted in the

introduction, the high level of uncertainty associated with MS can cause a great deal of anxiety for both patients and partners. Medical interventions, for most chronic illnesses, can only do so much, ultimately leaving one with an illness that can take a very uncertain course. When all else is out of one's control, the one thing a person can engage in is a method of relaxation, nurturance and self exploration. Through such a process one can mobilize one's psychological strengths and work to dispel one's psychological hindrances. The goal of this course was to help couples slow down their automatic pilot, in order to be present to their thoughts, emotions, and bodily sensations. For some, this process may have been quite difficult; for others, it was exhilarating. Some elements such as anxiety alleviation seemed to have an overall positive effect, while other elements affected only some. Still, according to participants' self report, something stirred in them. This awakening seemed to be unanimously welcomed by participants.

Ultimately, a time of illness is a time of stirring. If we can be the ones holding the spoon rather than the ones spinning within, we have that much more of a chance to make conscious decisions about our role within the story. MS is a story that begins and ends and begins again without any clear plotline for many; so, too, is meditation – a consistent exploration hoping to awaken a constant beginner's mind. As one learns to listen to each breath as a new discovery, one can also learn to explore one's illness not only as a negative – but also as a way into a story, leading to a set of new discoveries. Indeed, some participants expressed that they were actually grateful for MS, as it led them to reevaluate their lives, leading them to live more fully and openly.

Study Implications

Implications for Mindfulness and Psychotherapy

By allowing one to examine one's own fears, anxieties and reactions as a neutral observer of one's own mind, MBSR can help shift deep patterns in one's psychology. Nevertheless, as noted above, there are also times when meditation is not enough, where it might awaken or instigate an awareness of certain fears, anxieties, or even realities, leading one to require greater support than before. For some, mindfulness may alleviate the need for psychotherapy, but for others it may be a first step towards a journey of greater awareness, leading one to seek out support in individual or couple therapy.

Implications for MBSR Couple Treatment for MS

As noted above, MBSR has been shown to reduce anxiety. This study focused on a new patient population – couples where one member has MS. In this population, mostly patients exhibited a change in anxiety. Importantly, patients reported significantly higher anxiety than partners pre-treatment. The MBSR intervention alleviated patients' anxiety and brought them to a similar anxiety level as their partners.

In what ways can this intervention thus affect couples? It is possible that patients and partners would be able to communicate more effectively about the illness in the future. Additionally, since anxiety would be less polarized for patients, patients may be able to behave more independently and rely less on their partners. Thus, it is very possible that the relationship could benefit from this change in patient anxiety.

Second, while patient physical symptoms did not change as a result of the treatment, this too can be a possible longterm effect of treatment. There has been much research on the connection between chronic stress and its effect on the immune system

and longterm illness (McEwan, 2002). Many patients in the MBSR groups pondered whether they believed that increased anxiety correlated with relapses. Whether there is a direct correlation between MS relapse and anxiety or not, it is possible that as patient stress is abated, their physical health will be affected as well, and certainly their ability to cope with the effects of MS no matter how devastating the disease may turn out to be.

Implications for Couples and Illness Theory

Previous researchers have noted that "couples react to disase as a unit" and that interventions for patients should thus include partners as well (Pakenham, 1998, p. 269). In this study, patients and partners were indeed shown to be correlated in perceptions of illness uncertainty and uncertainty intolerance. Patients and partners were not correlated in anxiety levels in the beginning of treatment, as patients reported greater anxiety than partners. It is possible that part of the reduction of anxiety in this treatment was due to having the couple partner take part in the intervention. However, because there was no comparison group of patients only in this study, it is unclear whether having partners participate had a unique effect on the patients' distress. What we do know changed for both partners is the level of uncertainty tolerance, as well as their self-reported increase in ability to communicate about MS. Since MS is a chronic illness, it affects the family unit in many aspects. Some of the questions in the IUS include an inability to plan or move forward; clearly a mutual alleviation in uncertainty intolerance could allow the family unit to go on about their lives even while sitting with the inevitable uncertainty of MS.

Finally, whereas the MBSR intervention clearly showed more gains for patients than partners, especially in anxiety alleviation, this study does substantiate previous researchers' recommendations to include both couple members. This conclusion stems

from the finding that couple satisfaction increased most when both partners adhered to treatment; while couples where neither member adhered to treatment did not fare as well in couple satisfaction, couples in which couple members differed in their treatment compliance fared worst of all. Although a non-significant trend, if this finding were to be substantiated it would carry a powerful warning for psychological interventions for patients: while a patient can benefit individually from a skills training, the couple may be affected for the worse as the patient changes. Since it is not the intention of such interventions to hurt the patient's relationship, interventions would best be addressed to couples "as a unit," for this would be a way to ensure not only the patient receiving the best effect of the intervention, but also the patient's relationship.

Limitations of the Current Study

This study had several limitations which could be improved upon in future research. First, the sample size is small. In order to extrapolate more globally from this research, many more couples would need to be recruited. Additionally, T1 and T2 differ in many regards. Because there are multiple demographic differences between T1 and T2, this makes it difficult to determine which components may lead to different treatment effects. For example, race, income, years with partner, length of illness, etc. all could lead to potentially different outcomes for participants. Because the samples are small it is difficult to statistically control for all of these differences as well.

Second, in the first treatment group some participants left certain items blank. Unfortunately, this rendered those forms unscoreable, and their data had to be discarded, leading to an even smaller sample size for some of the scales. As a result, in the second

treatment group, each form was double checked so that no items were left unintentionally blank. Thus, the data for T1 and T2 were unbalanced, with more data available for T2.

Third, participants varied in their "homework" completion. Past studies have shown that MBSR participants who practice more at home show better results in anxiety reduction, etc. (Carmody and Baer, 2007). While participants in the current study were given a log in which to keep track of their homework practice, these logs were never requested to be turned in to the researcher. Thus, there is no record of how much exactly each participant practiced. Instead, "high meditators" and "low meditators" were distinguished by self report of time and amount of meditation by week eight. Indeed, results did indicate that those who adhered to treatment and meditated often did have better outcomes. Nevertheless, results could be more exact if an ongoing homework record had been kept.

Fourth, the study did not collect important data regarding whether subjects experienced a relapse during the intervention. Clearly, this could affect their sense of well being.

Finally, the lack of a randomized control presents an important limitation as there is no group to compare this population to. Specifically, it would have been beneficial to provide a control in which subjects received a non-MBSR group intervention for couples where one patient had MS to test the specific efficacy of MBSR. Alternatively, comparing groups of patients with groups of couples utilizing the MBSR intervention would have also been interesting. It is possible that subjects who were autonomous and determined enough were the ones who were also able and willing to commit to this eight week intervention.

Directions for Future Research

In future research, a randomized control study would allow the researcher to acquire an unbiased estimate of the treatment effect across a diverse group of participants. By necessity, the size of individual treatment groups cannot be very large, meaning that a number of intervention and control groups would have to be studied.

Future studies could focus on recruiting particular demographic populations in order to ascertain how the treatment interacts with different variables. Some of these may include sexuality, race, years with MS, length of marriage etc. Further, since homework completion was an important component of study results, further research could focus on what kind of elements encourage and promote adherence to homework.

Another element to explore further is the use of MBSR for couples facing illness. For example, it may be beneficial to compare three groups: a treatment group of couples, a treatment group of patients only, and a control group. A possible fourth group could be for partners only. Such research would contribute greatly to the field, as so many previous studies recommended couple interventions (Rolland, 1985, Schwartz & Kraft , 1996, Pakenham, 1998), and while this one followed these recommendations, these kinds of comparisons could better clarify in how couple interventions can be most beneficial.

Other illnesses would be interesting to explore as couple interventions. It would be interesting to see if MBSR would be similarly helpful for various illnesses, especially since anxiety is often associated with chronic illness, as is uncertainty. While many illnesses have been studied with MBSR, none – other than one study which included diet intervention for prostate cancer (Saxe et al., 2001) -- have been examined with MBSR as

a couple intervention. There are, however, future endeavors addressing couples. I have been invited to be the interventionist in a funded study for couples facing Prostate Cancer at Evanston Northwestern Hospital. Additionally, a grant proposal has been submitted for partners and patients with Alzheimer's at Virginia Commonwealth University.

Finally, during recruitment, many MS patients who were in the Progressive stage of their illness called with interest. They expressed that interventions such as this were extremely rare, and especially rare as couple interventions. Although their uncertainty is different than those with Relapse-Remitting diagnoses, they certainly do have a great deal of anxiety and uncertainty. Thus, it would be interesting for future studies to examine treatment effects of MBSR for MS participants in the various illness stages.

Conclusion

This study set out to examine the effect of MBSR on the anxiety, uncertainty and relationship of couples facing a Relapse-Remitting diagnosis of Multiple Sclerosis. The findings of this study indicated significant positive change in patients' anxiety levels and patient and partners' tolerance of uncertainty. While there was no apparent global significant change in the relationship as measured by the DAS, 22 of the 25 couples reported that they felt they were better able to communicate with their partners in general and about the illness, and that they felt their relationship had improved overall as a result of the MBSR training. Physical symptoms remained unchanged after the intervention.

While the study was limited by sample size and lack control sample, it adds to our understanding of skills interventions for couples facing chronic illness. Future studies would benefit from larger numbers, randomized control samples, comparisons of couple interventions vs. patient only interventions, and MBSR groups targeted at couples facing

other chronic illnesses. Further theoretical explorations of MBSR and change would also be a welcome addition to the ever-growing theoretical body of literature on the subject.

As chronic illness continues to haunt millions of Americans, within a Western "fix-it" medical culture, it is important to offer non-medical complementary psychological alternatives. The goal is to allow people to sit with uncertainty and to open the lines of communication with family members. Ultimately, our goal in chronic illness can shift from trying to fix the unfixable, in order to allow for being with and accepting what is, learning to strengthen and widen our own capacity to listen and embrace the moment in all of its complexity.

Appendices

Appendix A: Couple Similarity Scores: t Tests

	Test Value = 0					
					95% Confidence Interval of the Difference	
	t	df	Sig. (2-tailed)	Mean Difference	Lower	Upper
c_das_dif	.856	17	.404	3.61111	-5.2849	12.5071
c_becka_dif	1.945	16	.070	.14566	-.0131	.3044
c_saia_dif	1.610	17	.126	.28056	-.0872	.6483
c_taia_dif	1.548	17	.140	.21111	-.0767	.4989
c_iusa_dif	2.768	18	.013	.74493	.1794	1.3104
c_muisa_dif	1.252	18	.227	.16140	-.1094	.4322
c_dycons_dif	.322	16	.751	.88235	-4.9229	6.6876
c_affect_dif	-.572	17	.575	-.44444	-2.0825	1.1936
c_satis_dif	1.169	16	.260	1.29412	-1.0533	3.6416
c_cohes_dif	1.523	16	.147	1.76471	-.6912	4.2206

Appendix B: Couple Combined Scores: ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
c_das_dif	Between Groups	858.694	3	286.231	.875	.478
	Within Groups	4581.583	14	327.256		
	Total	5440.278	17			
c_becka_dif	Between Groups	.076	3	.025	.228	.875
	Within Groups	1.450	13	.112		
	Total	1.526	16			
c_saia_dif	Between Groups	1.026	3	.342	.579	.638
	Within Groups	8.270	14	.591		
	Total	9.296	17			
c_taia_dif	Between Groups	.386	3	.129	.339	.797
	Within Groups	5.307	14	.379		
	Total	5.693	17			
c_iusa_dif	Between Groups	10.394	3	3.465	3.613	.038
	Within Groups	14.383	15	.959		
	Total	24.777	18			
c_muisa_dif	Between Groups	1.400	3	.467	1.635	.223
	Within Groups	4.282	15	.285		
	Total	5.683	18			
c_dycons_dif	Between Groups	130.615	3	43.538	.296	.827
	Within Groups	1909.150	13	146.858		
	Total	2039.765	16			
c_affect_dif	Between Groups	19.528	3	6.509	.553	.655
	Within Groups	164.917	14	11.780		
	Total	184.444	17			
c_satis_dif	Between Groups	130.913	3	43.638	2.800	.082
	Within Groups	202.617	13	15.586		
	Total	333.529	16			
c_cohes_dif	Between Groups	39.392	3	13.131	.524	.673
	Within Groups	325.667	13	25.051		

		Sum of Squares	df	Mean Square	F	Sig.
c_das_dif	Between Groups	858.694	3	286.231	.875	.478
	Within Groups	4581.583	14	327.256		
	Total	5440.278	17			
c_becka_dif	Between Groups	.076	3	.025	.228	.875
	Within Groups	1.450	13	.112		
	Total	1.526	16			
c_saia_dif	Between Groups	1.026	3	.342	.579	.638
	Within Groups	8.270	14	.591		
	Total	9.296	17			
c_taia_dif	Between Groups	.386	3	.129	.339	.797
	Within Groups	5.307	14	.379		
	Total	5.693	17			
c_iusa_dif	Between Groups	10.394	3	3.465	3.613	.038
	Within Groups	14.383	15	.959		
	Total	24.777	18			
c_muisa_dif	Between Groups	1.400	3	.467	1.635	.223
	Within Groups	4.282	15	.285		
	Total	5.683	18			
c_dycons_dif	Between Groups	130.615	3	43.538	.296	.827
	Within Groups	1909.150	13	146.858		
	Total	2039.765	16			
c_affect_dif	Between Groups	19.528	3	6.509	.553	.655
	Within Groups	164.917	14	11.780		
	Total	184.444	17			
c_satis_dif	Between Groups	130.913	3	43.638	2.800	.082
	Within Groups	202.617	13	15.586		
	Total	333.529	16			
c_cohes_dif	Between Groups	39.392	3	13.131	.524	.673
	Within Groups	325.667	13	25.051		
	Total	365.059	16			

Appendix C: Descriptive Statistics

	Treatment 1			Treatment 2			Treatment (1 & 2)		
Variable	N	Mean	SD	N	Mean	SD	N	Mean	SD
Age	14	47.357	13.339	24	49.208	12.762	38	48.526	##
Female	14	0.571	-	24	0.625	-	38	0.605	-
Non-White	13	0.077	-	24	0.458	-	37	0.324	-
Unemployed	14	0.286	-	24	0.292	-	38	0.289	-
Income < 30K	14	0.000	-	24	0.000	-	38	0.000	-
Income 30K to 50K	14	0.072	-	24	0.249	-	38	0.184	-
Income 50K to 75K	14	0.286	-	24	0.292	-	38	0.289	-
Income 75K to 100K	14	0.071	-	24	0.292	-	38	0.211	-
Income > 100K	14	0.571	-	24	0.167	-	38	0.316	-
Unmarried	14	0.357	-	24	0.292	-	38	0.316	-
Years with Partner	14	21.282	14.972	24	14.000	13.293	38	16.683	##
Years Living with Partner	13	21.658	14.770	23	13.130	13.881	36	16.210	##
Has a child	14	0.643	-	24	0.417	-	38	0.500	-
Child living at home	14	0.500	-	24	0.250	-	38	0.342	-
Age at Diagnosis	13	40.077	10.813	24	33.583	12.137	37	35.865	##

References

Chronic Illness and Families

Boss, P. (2005). *Loss, trauma, and resilience: Therapeutic work with ambiguous loss.* New York: WW Norton.

Campbell, T. L. (1986). Family's impact on health: A critical review. *Family Systems Medicine,* 4, pp. 135-328.

Coyne, J. and Fiske, V. (1992). Couples coping with chronic and catastrophic illness. In J. Akamatsu,et al. (eds.), *Family health psychology*. Washington: Hemisphere Publishing.

Fisher, L., Ransom, D., Terry, H., Lipkin, M. Jr., & Weiss, R. (1992). The California Family Health Project: I. Introduction and a description of adult health. *Family Process,* 31, pp. 231-250.

Frank, A. (1998). Just listening: Narrative and deep illness. *Families, Systems, & Health,* 16(3), pp. 197-213.

Gonzalez, S., & Steinglass, P. (2002). Application of multifamily groups in chronic medical disorders. In W. F. McFarlane (Ed.) *Multifamily groups in the treatment of severe psychiatric disorders.* (pp. 315-341). New York: Guilford Press.

Imber-Black, E., Roberts, J., & Whiting, R. (eds.) (2003, 2nd ed.). *Rituals in families and family therapy.* New York: W.W. Norton.

Kleinman, A.M. (1988). *The illness narratives: Suffering, healing, and the human condition*. New York: Basic Books.

Moyers, B. (Producer). (1984). *A walk through the 20th century with Bill Moyers*. New York: PBS.

Olkin, R. (1999). *What psychotherapists should know about disability*. New York: Guilford Press.

Rando, T. A. (Ed.) (2000). *Clinical dimensions of anticipatory mourning: Theory and practice in working with the dying, their loved ones, and their caregivers.* Champaign IL: Research Press.

Reiss, D., Gonzalez, S. & Kramer, N. (1986). Family process, chronic illness, and death: On the weakness of strong bonds. *Archives of General Psychiatry*, 43: pp. 795-804.

Rolland, J. S. (1984). Toward a psychosocial typology of chronic and life-threatening illness, *Family Systems Medicine,* 2, pp. 245-263.

Rolland, J.S. (1994a). *Families, illness, and disability: An integrative treatment model.* New York: Basic Books.

Rolland, J.S. (1994b). In sickness and in health: The impact of illness on couple's relationship. *Journal of Marital & Family Therapy,* 20(4), pp. 327-347.

Steinglass, P. (1998). Multiple family discussion groups for patients with chronic medical illness. *Families, Systems, & Healt,*16, nos 1/2, pp. 55-71.

Thomas, A., & Chess, S. (1977). *Temperament and development.* New York: Brunner / Mazel.

Walsh, F. (1999). *Spiritual Resources in Family Therapy.* New York: Guilford.

Mindfulness Resources

Astin, JA (1997). Stress reduction through mindfulness meditation. *Psychotherapy Psychosomatics*, 66, pp. 97-106.

Astin, JA, Berman, BM, Bausell, B, Lee, WL, Hochberg, M, and Forys, KL (2003, Oct). The efficacy of mindfulness meditation plus Qigong movement therapy in the treatment of fibromyalgia: a randomized controlled trial. *Journal of Rheumatology*, 30(10), pp. 2088-9.

Bandura, A. (1977, Mar). Self-efficacy: toward a unifying theory of behavioral change. *Psychological Review*, 84 (2), pp. 191-215.

Bernhard, J., Kristeller, J. and Kabat-Zinn, J. (1988). Effectiveness of relaxation and visualization techniques as a adjunct to phototherapy and photochemotherapy of psoriasis. *Journal of the American Academy of Dermatology*, 19, pp. 572-73.

Bower, J, Woolery, A, Sternlieb, B, and Garet, D (2005, Jul). Yoga for cancer patients and survivors. *Cancer Control*, 12 (3), pp. 165-171.

Carlson, L., Speca, M., and Kamala D (2004, May). Mindfulness-based stress reduction in relation to quality of life, mood, symptoms of stress and levels of cortisol, dehydroepiandrosterone sulfate (DHEAS) and melatonin in breast and prostate cancer outpatients. *Psychoneuroendocrinology*, 29(4), pp. 448-474.

Carrington, Patricia (1993). **"**Modern Forms of Meditation." In Woolfolk, R. and Lehrer, P., Eds. *Principles and Practices of Stress Management* (pp. 139-168). New York, NY: The Guilford Press.

Chang, J. and Hiebert, B. (1989). Relaxation procedures with children: A review. *Medical Psychotherapy, an International Journal*, 2, pp.163-176.

Cowger, E. L, and Torrance, E. P. (1982). Further examination of the quality changes in creative functioning resulting from meditation (Zazen) training. *Creative Child and Adult Quarterly*, 7(4), pp. 211-217.

Davidson, Richard J (2004, Jan-Feb). Alterations in Brain and Immune Function Produced by Mindfulness Meditation": Comment Response. *Psychosomatic Medicine*, 66(1), pp.147-148.

Emavardhana, T. and Tori, C. D. (1997). Changes in self-concept, ego defense mechanisms, and religiosity following seven-day Vipassana meditation retreats. *Journal for the Scientific Study of Religion*, 36(2), pp. 194-206.

Goleman, D. J., & Schwartz G. E. (1976). Meditation as an intervention in stress reactivity. *Journal of Consulting and Clinical Psychology*, 44 (3), pp. 456-466.

Grossman, P., Niemann, L., and Schmidt, S (2004, Jul). Mindfulness-based stress reduction and health benefits: A meta-analysis. *Journal of Psychosomatic Research*, 57(1), pp. 35-43.

Harrington, A (1999, Ed.). *The Placebo Effect: An Interdisciplinary exploration*. Cambridge: Harvard University Press.

Harte, J. L., Eifert G. H., and Smith, R. (1995). The Effects on Running and Meditation on beta-endorphin, corticotrophin-releasing hormone and cortisol in plasma, and on mood. *Biological Psychology*, 40 (3), pp. 251-265.

Holroyd, K., Andrasik, F. & Noble, J. (1980). A comparison of EMG biofeedback and a credible pseudotherapy in treating tension headache. Journal of Behavioral Medicine. 3(1). Pp. 29-39.

Kabat-Zinn, J. (1982). An out-patient program in Behavioral Medicine for chronic pain patients based on the practice of mindfulness meditation: Theoretical considerations and preliminary results. *General Hospital Psychiatry*, 4, pp. 33-47.

Kabat-Zinn, J. (1990) *Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain and Illness*, Delacorte, NY: Delta Trade Paperbacks.

Kabat-Zinn, J. (2000, July). Participatory Medicine. *Journal of the European Academy of Dermatology and Venereolog*,. 14 (4), pp 239-240.

Kabat-Zinn, J., Lipworth, L. and Burney, R**.** (1985). The clinical use of mindfulness meditation for the self-regulation of chronic pain. *Journal of Behavioral Medicine*, 8, pp.163-190.

Kabat-Zinn, J., Lipworth, L., Burney, R. and Sellers, W. (1986). Four year follow-up of a meditation-based program for the self-regulation of chronic pain: Treatment outcomes and compliance. *Clinical Journal of Pain*, 2, pp.159-173.

Kabat-Zinn, J. and Chapman-Waldrop, A. (1988). Compliance with an outpatient stress reduction program: rates and predictors of completion. *Journal of Behavioral Medicine*, 11, pp. 333-352.

Kabat-Zinn, J., Massion, A.O., Kristeller, J., Peterson, L.G., Fletcher, K., Pbert, L., Linderking, W., Santorelli, S.F. (1992). Effectiveness of a meditation-based stress reduction program in the treatment of anxiety disorders. *American Journal of Psychiatry*, 149, pp. 936-943.

Kabat-Zinn, J. Chapman, A, and Salmon, P. (1997). The relationship of cognitive and somatic components of anxiety to patient preference for alternative relaxation techniques. *Mind/ Body Medicine*, 2, pp.101-109.

Kabat Zinn, J, Relman, A, Riley, D., Hosmer, D, Dossey, L (2001). Parsing the Data: An examination of a study on meditation and the treatment of psoriasis: A critical exchange. *Advances in Mind-Body Medicin*e, 17, pp 66-77.

Kabat-Zinn, J., Wheeler, E., Light, T., Skillings, A., Scharf, M.S., Cropley, T. G., Hosmer, D., and Bernhard, J. (1998). Influence of a mindfulness-based stress reduction intervention on rates of skin clearing in patients with moderate to severe psoriasis undergoing phototherapy (UVB) and photochemotherapy (PUVA). *Psychomatic Medicine*, 60, 625-632.

Libo, L. and Arnold, G. (1983). Relaxation practice after biofeedback therapy: A long-term follow-up study of utilization and effectiveness. *Applied Psychophysiology and Biofeedback*, 8(2), pp. 217-227.

MacLean, C., Walton, K. G., Wenneberg, S. R., Levitsky, D. K, Mandarino, J. P., Waziri, R., Hillis, S. L., & Schneider, R. H. (1997). Effects of the transcendental meditation program on adaptive mechanisms: Changes in hormone levels and responses to stress after 4 months of practice. *Psychoneuroendocrinology*, 22 (4) pp. 277-295.

Miller, J., Fletcher, K., & Kabat-Zinn, J. (1995). Three-year follow-up and clinical implications of a mindfulness-based intervention in the treatment of anxiety disorders. *General Hospital Psychiatry*, 17, pp. 192-200.

Ornish, D.(1998). *Love and Survival. The Scientific Basis for the Healing Power of Intimacy.* New York: Harper Collins.

Reibel, Diane K.; Greeson, Jeffrey M.; Brainard, George C. (2001, Jul-Aug). Mindfulness-based stress reduction and health-related quality of life in a heterogeneous patient population. General Hospital Psychiatry, 23(4), pp. 183-192.

Roth, B. and Robbins, D. (2004, Jan-Feb). Mindfulness-based stress reduction and health-related quality of life: Findings from a bilingual inner-city patient population**.** *Psychosomatic Medicine*, 66(1), pp. 113-123.

Sagula, D. and Rice, K. (2004, Dec.). The Effectiveness of Mindfulness Training on the Grieving Process and Emotional Well-Being of Chronic Pain Patients*. Journal of Clinical Psychology in Medical Settings*, 11(4), pp 333-342.

Saxe, G., Hebert, J., Carmody, J., Kabat-Zinn, J., Rosenzweig, P., Jarzobski, D., Reed, G., and Blute, R. (2001). Can Diet, in conjunction with Stress Reduction, Affect the Rate of Increase in Prostate-specific Antigen After Biochemical Recurrence of Prostate Cancer? *Journal of Urology*, 166, pp. 2202-2207.

Schneider, J, & Deutsch, D. (1997). Understanding the transformative potential of grief: Construct validation of the response to loss inventory. Traverse City, MI: Seasons Press.

Segal Z. V., Williams J. M. G., and Teasdale J. D. (2002) *Mindfulness-based Cognitive Therapy for Depression: a new approach to preventing relapse*. New York, NY: Guilford Publications.

Shapiro SL, Schwartz GE, Bonner G (1998). Effects of mindfulness-based stress reduction on medical and premedical students. *Journal of Behavioral Medicine*, 21, pp. 581-99.

Shapiro, Schwartz, & Santerre (2002). Snyder, C. R. (Ed); Lopez, Shane J. (Ed). (2002). *Handbook of positive psychology* (pp. 632-645). London, England: Oxford University Press.

Speca M, Carloson LE, Goodey E, and Angen M (2000). A randomized, wait-list controlled clinical trial: the effect of a mindfulness meditation-based stress reduction program on mood and symptoms of stress in cancer outpatients. *Psychosomatic Medicine*, 62, pp. 613-22.

Sridevi, K., Rao, P. & Krishna, V. (1998). Temporal effects of meditation and personality. *Psychological Studies.* 43 (3), pp. 95-105.

Taylor, D. N. (1995). Effects of a behavioral stress management program on anxiety, mood, self-eseteem and T-cell count in HIV-positive men. *Psychological Reports*, 76, pp. 451-7.

Woolfolk, R. and Lehrer, P. (1993). **"**Specific Effects of Stress Management Techniques." In Woolfolk, R. and Lehrer, P., Eds. *Principles and Practices of Stress Management*. New York, NY: The Guilford Press, pp. 481-520.

Multiple Sclerosis Resources

Barbarin, O, Hughes, D., & Chester, M. (1985). Stress, coping, and marital functioning among parents of children with cancer. *Journal of Marriage and the Family*, 47, pp. 473-580.

Boeije, Hennie R., Janssens**,** A. & Cecile J. W. (2004, Aug). 'It might happen or it might not': How patients with multiple sclerosis explain their perception of prognostic risk. *Social Science & Medicine*, 59(4), pp. 861-868.

Bourdette, D., Yadav, V, Shinto, L. (2004). Multiple Sclerosis. In: Oken BS, ed. *Complementary therapies in neurology: an evidence-based approach*. New York: Parthenon Publishing.

Brooks, N. and Matson, R. (1987). Managing Multiple Sclerosis. Resident Sociological Health Care, 6, pp. 73-106.

Buhr**,** K., & Dugas, M.J. (2002, Aug). The Intolerance of Uncertainty Scale: Psychometric properties of the English version. *Behaviour Research and Therapy*, 40(8), pp. 931-946.

Burman, B. and Margolin, G. (1992). Analysis of the association between marital relationships and health problems: An interactional perspective. *Psychological Bulletin*, 112, pp. 39-63.

Cohen, M. (1993). The unknown and the unknowable – Managing sustained uncertainty. *Western Journal of Nursing Research*, 15, pp. 77-96.

Crigger, N. (1996). Testing an uncertainty model for women with multiple sclerosis. *Advanced Nursing Science*, 18 (3), pp. 37-47.

Di Fabio, R. (1993). Extended out patient rehabilitaton for persons with progressive Multiple Sclerosis. *Archives of Physical Medicine*. 79, pp 114-146,

Gold-Spink, Erica, Sher, Tamara Goldman, & Theodos, Violet. (2000). Uncertainty in illness and optimism in couples with multiple sclerosis. *International Journal of Rehabilitation & Health*, 5(3), pp. 157-164.

Eeltink**,** Catharina, Duffy, Maureen, & Sperry, Len (2004, Jul). Restorying the illness experience in multiple sclerosis. *Family Journal: Counseling and Therapy for Couples and Families*, 12(3), pp. 282-286.

Holliday, S., Benfiel, P. (1997). Interferon: a review of pharmacological properties and therapeutic potential in Multiple Sclerosis. *Biological Drugs*, 8, pp. 317-330.

Janssens, A. C. J. W.; de Boer, J. B.; van Doorn, P. A. (2003a, May). *Expectations of wheelchair-dependency in recently diagnosed patients with multiple sclerosis and their partners. European Journal of Neurology,* 10(3), pp. 287-293.

Janssens**,** A. C. J. W., van Doorn, P. A., de Boer, J. B. (2003b, Dec). Impact of recently diagnosed multiple sclerosis on quality of life, anxiety, depression and distress of patients and partners. *Acta Neurologica Scandinavica*, 108(6), pp. 389-395.

Jopson**,** Nicola M.& Moss-Morris, Rona (2003). *The role of illness severity and illness representations in adjusting to multiple sclerosis. Journal of Psychosomatic Research*, 54(6), pp. 503-511.

Manne, S., & Zautra, A. (1989). Spouse criticism and support:Their association with coping and psychological adjustment among women with rheumatoid arhritis. *Journal of Personality and Scoial Psychology*, 56, pp. 608-617.

McLaughlin, Judith & Zeeberg, Ib. (1993, Aug). Self-care and multiple sclerosis: A view from two Cultures. *Social Science & Medicine*, 37(3), pp. 315-329.

McNulty, Kristy, Livneh, Hanoch, & Wilson, Lisa M (2004). Perceived Uncertainty, Spiritual Well-Being, and Psychosocial Adaptation in Individuals with Multiple Sclerosis. *Rehabilitation Psychology,* 49(2), May. pp. 91-99.

Mills**,** Nigel & Allen, Janet. (2000, Nov-Dec). Mindfulness of movement as a coping strategy in multiple sclerosis: A pilot study. *General Hospital Psychiatry*, 22(6), pp. 425-431.

Mills, N., Allen, J., Carey-Morgan, S. (2000). Does Tai Chi/Qi Gong help multiple sclerosis? A pilot study. *Journal of Bodywork Movement Therapy,* 4, pp. 39-48.

Mishel, Merle H., Braden**,** Carrie J. (1988, Mar-Apr). Finding meaning: Antecedents of uncertainty in illness. *Nursing Research*, 37(2), pp. 98-103, 127.

Mishel**,** Merle H. (1981, Sep-Oct). *The measurement of uncertainty in illness. Nursing Research*, 30(5), pp. 258-263.

Mullins, Larry L.; Cote, Max P. (2001, May). Illness intrusiveness, uncertainty, and distress in individuals with multiple sclerosis. Fuemmeler, Bernard F. *Rehabilitation Psychology,* 46(2), pp. 139-153.

Northouse, L., Dorris, G., & Charron-Moore, C. (1995). Factors affecting couples' adjustment to recurrent breast cancer. *Social Science and Medicine*, 41, pp. 69-76.

Noseworthy, J., Lucchinetti, C., Rodriguez, M., Weinshenker, B. (2000, Sept). Multiple Sclerosis. *New England Journal of Medicine,* 343 (13), pp. 938-956.

Oken, B.S., Kishiyama, S, Zajdel, D., Bourdette, D., Carlsen, J., Haas, M., Hugos, C., Kraemer, D.F., Lawrence, J. and Mass, M. (2004). Randomized controlled trial of yoga and exercise in multiple sclerosis. *American Academy of Neurology*, 62, pp. 2058-2064.

Pakenham, Kenneth I. (1998, Jul). Couple coping and adjustment to multiple sclerosis in care receiver-carer dyads. *Family Relations: Interdisciplinary Journal of Applied Family Studies*, 47(3), pp. 269-277.

Pakenham, K, Dadds, R, and Rogers, A (1995). Carers' Burden and Adjustment to HIV. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV,* 1360-0451, 7(2), pp.189-203.

Revenson, Tracy (1994). Social support and marital coping with chronic illness. *Annals of Behavioral Medicine*, 16, pp. 122-130.

Schwartz, Lauren, & Kraft, George H (1999, Nov/Dec). The Role of Spouse Response to Disability and family Environment in Multiple Sclerosis. *American Journal of Physical Medicine & Rehabilitation,* 78(6), pp. 525-532.

Wineman, Nancy M. (1990, Sep-Oct). Adaptation to multiple sclerosis: The role of social support, functional disability, and perceived uncertainty. *Nursing Research*, 39(5), pp. 294-299.

Wineman, NM, O'Brien, RA, Nealon, NR, & Kaskel, B. (1993, Dec.) Congruence in uncertainty between individuals with multiple sclerosis and their spouses. *The Journal of Neuroscience Nursing*, 25(6), pp. 356-61.

Wineman, NM, Schwetz, KM, Goodkin, DE, & Rudick R. (1996).Relationship among illness uncertainty, stress, coping and emotional well-being at entry into a clinical drug trial. *Applied Nursing Research*, 9, pp. 53-60.

Wineman, N., Schwetz, K., Goodkin, D., & Rudick R. (1997).Relationship among illness uncertainty, stress, coping and emotional well-being at entry into a clinical drug trial. *Applied Nursing Research*, 9, pp. 53-60.

Measures

Beck, A., Epstein, N.,Brown, G. & Steer, R. (1988). An Inventory for Measuring Clinical Anxiety: Psychometric Properties. Journal of Consulting and Clinical Psychology, 56 (6), pp. 893-897.

Buhr, K and Dugas, M. (2002). The intolerance of uncertainty scale: psychometric properties of the English version. *Behaviour Research and Therapy,* 40 (8), pp. 931-945.

Carey, M., Spector, I., Lantiga, L., & Krauss, D. (1993). Reliability of the Dyadic Adjustment Scale. *Psychological Assessment,* 5 (2), pp. 238-40.

Crane, D., Allgood, S., Larson, J., & Griffin, W. (1990). Assessing marital quality with distressed and nondistressed couples: A comparison and equivalency table for three frequently used measures. *Journal of Marriage and the Family,* 52, pp. 87-93.

Cassileth, B. (1992). Information and participation preferences among cancer patients. Annual Internal Medicine, 92, pp. 832-836.

Dugas, M.J., Freeston, M.H. and Ladouceur, R., 1997. Intolerance of uncertainty and problem orientation in worry. *Cognitive Therapy and Research* 21, pp. 593–606.

Eddy, J., Heyman, R., & Weiss, R. (1991). An empirical evaluation of the Dyadic Adjustment Scale: Exploring the differences between marital "satisfaction" an "adjustment." *Behavioral Assessment,* 13, pp. 199-220.

Gulick, E. (1988). The Self-Administered ADL Scale for Persons with Multiple Sclerosis. *Nursing Research,* 38 (3), May/June, pp. 147-153.

Gulick, E. (1989). Model Confirmation of the MS-Related Checklist. *Nursing Research*, 38, 147-153.

Freeston, M.H., Rhéaume, J., Letarte, H., Dugas, M.J. and Ladouceur, R., 1994. Why do people worry? *Personality and Individual Differences* 17, pp. 791–802.

Kurdeck, L. (1992). Dimensionality of the Dyadic Adjustment Scale: Evidence from heterosexual and homosexual couples*. Journal of Family Psychology*, 6, pp. 22-35.

Mishel, M. (1981). The Measurement of Uncertainty in Illness. *Nursing Research,* 30 (5), pp. 258-263.

Mishel, M. (1984). Perceived Uncertainty in Illness. Research in Nursing Health., 7(3), pp. 163-71.

Osman, A., Kopper, B, Francisco, X., Barrios, J., Osman, R., & Wade, T. (1997). The Beck Anxiety Inventory: Reexamination of Factor Structure and Psychometric Properties. *Journal of Clinical Psychology*, 53,(1), pp. 7-14.

Ramaniah, M., Franzen, N., & Schill, T. (1983). A Psychometric Study of the State-Trait Anxiety Inventory. *Journal of Personality Assessment*, 47, pp. 531-545.

Robichaud, M., & Dugas, M. J. (2000, Nov). Do men and women worry differently? An investigation of gender effects on a cognitive-behavioural model of worry and anxiety. *Poster presented at the annual convention of the Association for Advancement of Behavior Therapy*, New Orleans, LO.

Spanier, G. (1976). Measuring dyadic adjustment: New scales for assessing the quality of marriage and similar dyads. *Journal of Marriage and the Family*, 38, pp. 15-28.

Spanier, G. (1988). Assessing the strengths of the Dyadic Adjustment Scale. *Journal of Fmaily Psychology*, 2, pp. 92-94.

Spielberger, C. (1983). Manual for the State-Trait Anxiety Inventory (Form Y). Palo Alto: California. Consulting Psychologists Press.

Vallerand, R.J., 1989. Vers une méthodologie de validation transculturelle de questionnaires psychologiques: Implications pour la recherche en langue francaise [Toward a transcultural validation methodology of psychological questionnaires: Implications for French language research]. *Psychologie canadienne,* 30, pp. 662–680.

Volicer, B., 1977. Medical-surgical differences in hospital stress factors. *Journal of Human Stress*, 3, pp. 3-13.