

## Uncertainty in Illness and Optimism in Couples With Multiple Sclerosis

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*We examined relationships among uncertainty in illness, optimism, symptom severity, and depression in 18 individuals with Multiple Sclerosis (MS) and their partners. Participants are part of an ongoing study in which they complete assessments every 3 months for approximately 1 year. Preliminary analyses indicate some similarities as well as some differences in responses between individuals with MS and their partners. Specifically, results indicated a very strong positive correlation between patients' and partners' levels of uncertainty regarding the illness. Differences in responding were evident when comparing levels of depression with uncertainty. Levels of depression in patients positively related to levels of uncertainty in their partners. Preliminary results also suggest negative correlations between patients' levels of optimism and levels of uncertainty in both partners. Future analyses will focus on whether these relationships remain constant over time.*

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**KEY WORDS:** optimism; uncertainty; depression; couples; Multiple Sclerosis (MS).

In the United States and Europe, Multiple Sclerosis (MS) is the neurological disease most commonly acquired by young adults, affecting women twice as often as men (Mohr *et al.*, 1999; Pakenham, 1999). The central nervous system (CNS) becomes compromised in patients suffering from MS, and current thought is that plaques or lesions form on myelin sheath surrounding axons in the CNS as a result of the immune system attacking itself.

Severity of MS can vary greatly within and among individuals. Many individuals exhibit steady and sometimes rapid deterioration, but others experience few symptoms and a relatively mild to moderate course characterized by relapses and remissions. Further, the course of the illness can shift at any time (Lublin and Reingold, 1996). Symptoms of MS can include loss of function or feeling in limbs, loss of bowel or bladder control, sexual dysfunction, fatigue, changes in vision, loss of balance, pain, changes in cognitive functioning, and emotional changes (Goodkin, 1992; Mohr and Dick, 1998). Unfortunately, there is no known etiology for MS and no cure, and current treatments provide only minimal, symptomatic relief (Rao *et al.*, 1992). These characteristics complicate adjustment to the illness.

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In general, individuals with MS exhibit a higher prevalence of emotional disorders relative to other patient groups with comparable degrees of physical disability (Rao *et al.*, 1992). Depression is the psychological symptom most frequently associated with MS, with a lifetime prevalence of about 42% (Rao *et al.*, 1992; VanderPlate, 1984). Patients with MS have higher rates of depression than found in either the general population or in individuals with other medical or neurological illnesses (Schubert and Foliart, 1993). Of interest, however, is that although some research has indicated a positive correlation between severity of MS and depression (McIvor *et al.*, 1984), results are equivocal (Maybury and Brewin, 1984). Additionally, those with MS often experience high levels of anxiety (Maurelli *et al.*, 1992).

Frequency of divorce among couples where one partner suffers from MS is approximately twice that of the general population (Brooks and Matson, 1987). This finding is consistent with a review of marital literature suggesting an association between the experience of a chronic illness in an intimate relationship and low levels of relationship satisfaction (e.g., Burman and Margolin, 1992; Hafstrom and Schram, 1984; Siegel, 1986).

Additionally, levels of uncertainty about the illness is an important element in both couple and individual adjustment to the illness. Although researchers have not explored this factor in relation to MS, Northouse *et al.* (1995) found significant differences in levels of uncertainty between partners who are experiencing recurrent breast cancer. Specifically, husbands reported higher levels of uncertainty than their wives. However, the women reported more emotional distress than their husbands. Other research on breast cancer suggests that both patients and partners report high levels of uncertainty related to the illness (Chekryn, 1984) and that there is a negative correlation between levels of uncertainty and level of adjustment (i.e., as uncertainty increases, adjustment decreases; Mishel *et al.*, 1984).

Examination of the relationship between optimism and illness has indicated a relationship between optimism and physical and psychological well-being (Brenner *et al.*, 1994; Carver *et al.*, 1993; Epping-Jordan *et al.*, 1999; Lai, 1994; Miller *et al.*, 1996; Scheier and Carver, 1985, 1987, 1992). Overall these findings suggest that optimism may serve as a buffer against depression and may allow individuals (and couples) to adjust to the illness with less difficulty than would be the case if they did not have an optimistic disposition.

We conducted the current investigation in order to further understand psychological sequelae of MS within individuals. Additionally, it was of interest to examine psychological effects of MS on intimate partners of MS patients. Because the course of MS is so unpredictable, we hypothesized that both MS patients and their partners would have difficulty understanding the illness and adjusting to it and that levels of optimism would relate to levels of adjustment. We also hypothesized that as a chronic illness, MS would negatively impact relationships of MS patients and their partners.

## METHOD

### Participants

We sent packets of questionnaires to 29 couples recruited from a national Multiple Sclerosis Day workshop. Eighteen couples, plus two additional individuals whose partners did not complete the questionnaires, responded. We excluded from the present study the participants whose partners did not complete the questionnaires. The study sample ( $n = 18$

couples) includes two subsamples, recruited 1 year apart. The participants are part of an ongoing study that assesses participants approximately every 3 months for 1 year. The participants all indicated a willingness to participate in a study about effects of MS on couple functioning. We interviewed all volunteers over the telephone to assure that they met the following inclusion criteria:

1. Participants had to be in a marital relationship or living with an intimate partner for at least six months;
2. both partners were willing to participate;
3. at least one of the partners had received a diagnosis of MS from a qualified medical professional; and
4. neither partner suffered from a psychotic disorder.

Participation in this study was entirely voluntary, and couples did not receive financial compensation for their participation. All of the participants were Caucasian and involved in heterosexual relationships. The average age of the patients was 46.33 ( $SD = 9.77$ ), and average age of the partners was 46.89 ( $SD = 9.71$ ). Seventy-eight percent of the patients were female ( $N = 14$ ), and 22% were male ( $N = 4$ ). The gender ratio of this sample is consistent with MS literature. The mean number of years since receiving the diagnosis was 11.31 ( $SD = 7.51$ ), and the number of years in treatment for MS was 9.47 ( $SD = 8.54$ ). Sixteen of the couples were in a marital relationship (89%), and two couples were in a partner relationship (11%). Forty-four percent of the patients and 100% of the partners reported current gainful employment, and the mean estimated household income was \$64,361 ( $SD = \$26,362$ ). Eighty-nine percent of the couples have children.

### Procedure

MS patients and their partners completed the following self-report measures: (a) Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977), (b) Life Orientation Test (LOT; Scheier and Carver, 1985), (c) Dyadic Adjustment Scale (DAS; Spanier, 1976), and (d) Mishel Uncertainty in Illness Scale (MUIS; Mishel, 1981). The partners of the individuals with MS completed the version of the MUIS created for family members (PPUS; Mishel, 1983). Additionally, patients completed the Activities of Daily Living Self-Care Scale for Persons with MS (ADL-MS; Gulick, 1988). We mailed participants all questionnaires and provided participants with stamped, self-addressed envelopes for returning all materials. We instructed participants that upon receiving the packet of materials, they were to complete the questionnaires independently from their partners and were not to share their responses with their partners until after they returned the packets. We also asked them to return the completed questionnaires within approximately 1 month from receiving them. Participants failing to return questionnaires in a timely fashion received reminder phone calls.

### Measures

#### *Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977)*

The CES-D is a well-validated, 20-item scale that measures frequency and intensity of depression symptoms that have occurred during the past week. We selected this

particular measure because of its extensive use with adults with physical disabilities (Coyle and Roberge, 1992). Items get scored on a 4-point scale (0–3), with total scores ranging from 0 to 60; the higher the score the greater the number of symptoms of depression. Scores greater than 16 identify people who may be in need of diagnostic follow-up services for clinical depression (Myers and Weissman, 1980; Roberts and Vernon, 1983).

*Life Orientation Test (LOT; Scheier and Carver, 1985)*

The LOT is a unidimensional measure of dispositional optimism. It consists of eight items plus four filler items. All of the items are face valid and inquire about an individual's tendency to have favorable expectations of future events. Half of the items are optimistically phrased items, and half are pessimistically phrased items. Participants state their level of agreement with each item on a 4-point scale from 0 (strongly disagree) to 4 (strongly agree). High scores on this measure are indicative of high levels of optimism, and low scores are indicative of low levels of optimism.

*Dyadic Adjustment Scale (DAS; Spanier, 1976)*

The DAS is a well-validated, 32-item measure that is one of the most commonly used measures of marital satisfaction (Epstein and Baucom, 1988). High scores on this scale indicate high levels of marital satisfaction and low scores indicate low levels of satisfaction. We used this scale to assess global marital/relationship satisfaction as perceived by each individual in the couple relationship.

*Mishel Uncertainty in Illness Scale (MUIS; Mishel, 1981)*

The MUIS is a measure of the patient's level of uncertainty about their illness. The MUIS consists of 34 items. We also used the version created for family members (PPUS; Mishel, 1983), consisting of 31 items, to assess partners' levels of uncertainty about the illness in the individual with MS. Both questionnaires assess the amount of ambiguity, complexity, deficient information, and unpredictability that patients and their family members have about the patient's illness. High scores on both versions indicate high levels of uncertainty, and low scores indicate low levels of uncertainty.

*Activities of Daily Living Self-Care Scale for Persons With MS (ADL-MS; Gulick, 1988)*

The ADL-MS assesses frequency with which individuals with MS are able to perform a variety of activities without assistance from others. Participants rate each activity on a 6-point scale from 0 (never) to 6 (always). Participants rate their level of functioning on a typical day. The total score ranges from 0 to 75, with high scores indicating high levels of ADL functioning. We used this measure to assess symptom severity in individuals with MS.

**Table I.** Relationship Among Patient Uncertainty, Depression, and Optimism

	Uncertainty	Depression	Optimism
Uncertainty		.616**	-.678**
Depression	.616**		-.737**
Optimism	-.678**	-.737**	

\*  $p < .05$ , two-tailed. \*\*  $p < .01$ , two-tailed.

### RESULTS

Because of the small sample size, analyses consisted primarily of bivariate correlations. Results indicated a significant positive correlation between patients' levels of depression and uncertainty ( $r = .616, p < .01$ , Table I). Additionally, patients' levels of depression positively correlated with partners' levels of uncertainty ( $r = .559, p < .05$ , Table II). Results also indicated a significant negative correlation between patients' optimism and depression ( $r = -.737, p < .01$ , Table I). Negative correlations were also present between patients' levels of optimism and their levels of uncertainty ( $r = -.678, p < .01$ , Table I) as well as their partners' levels of uncertainty ( $r = -.655, p < .01$ , Table II).

Study results also indicated a very strong positive correlation between patients' and partners' levels of uncertainty ( $r = .989, p < .01$ , Table II). This relationship appeared to be independent of scores on the depression measure, suggesting that they are two separate constructs. Finally, a trend approaching significance was evident between level of functioning of patients (as measured by the ADL-MS) and level of marital/relationship satisfaction reported by their partners, suggesting that patients who reported high levels of ADL functioning had partners who reported high levels of relationship satisfaction.

### DISCUSSION

One of the unique aspects of this study was examination of relationships among depression, optimism, and level of functioning both within and among the couples involved. Consistent with previous findings (Rao *et al.*, 1992; Vanderplate, 1984), results indicated a positive relationship between patients' levels of depression and uncertainty. There are a number of possible explanations for this association. It is possible that depression causes patients to view the information they receive as ambiguous. It is also likely that the fluctuating or ambiguous nature of the illness and its related symptoms cause individuals to feel depressed. Depression is, in fact, often a symptom of MS (Gilchrist and Creed, 1994; Joffe *et al.*, 1987). It is also a possibility that the often chronic nature of the illness results in depression. Future prospective studies are necessary to address this issue. Also, studies

**Table II.** Relationship Between Patient Uncertainty, Depression, and Optimism With Partner Uncertainty

	Patient uncertainty	Patient depression	Patient optimism
Partner uncertainty	.989**	.559*	-.655**

\*  $p < .05$ , two-tailed. \*\*  $p < .01$ , two-tailed.

examining communication between caregivers and patients with MS would help clarify the origin of ambiguity patients are reporting.

Results from the current study also indicate that patients' optimism and depression inversely relate to each other, thereby providing support for previous research that has found an association between optimism and favorable psychological outcomes (Brenner *et al.*, 1994; Carver *et al.*, 1993; Epping-Jordan *et al.*, 1999; Lai, 1994; Miller *et al.*, 1996; Scheier and Carver, 1985, 1987, 1992). The negative relationship between patients' optimism and levels of uncertainty may be due, in part, to the tendency of optimists to expect generally favorable outcomes to events. This explanation may lead patients to perceive ambiguous information they receive about their condition as neutral or positive, particularly when compared with their pessimistic counterparts. Optimistic patients may also be more likely than pessimistic patients to believe that they have limited impairment and thus may report fewer and less debilitating physical symptoms than do pessimistic patients (Lai, 1994). This particular hypothesis did not receive support from the current findings. However, it will be of interest to see if this trend continues across time.

One of the most interesting findings was the strong positive relationship between patients' and partners' high levels of uncertainty. There are several possible reasons for this finding. First, health-care providers may be supplying couples with inconsistent, ambiguous information about the disease process. This may be because the course of the disease is so variable across time and individuals, or health-care providers may not be communicating effectively with couples and vice versa. Another possibility is that the information gets filtered through patients who, because of the inherent content of the information or because of issues relating to depression, are communicating their feelings of uncertainty to their partners, thereby influencing their levels of uncertainty as well. It is this last relationship that is of particular interest and may help to guide future research.

Finally, results from the current study indicated a trend between patients' level of functioning and level of marital/relationship satisfaction reported by their partners, with high levels of functioning associated with high levels of relationship satisfaction. It is possible that partners may feel more satisfied in relationships with patients who have high levels of functioning than with patients with low levels of functioning because there is less caregiver burden for high functioning patients than for low functioning patient. However, this trend may be present because, as in many other chronically ill populations, there exists an association between high levels of social support and low numbers of symptoms of physical distress (e.g., Gulick, 1994; Wethington and Kessler, 1986).

Interestingly, although researchers have noted a general relationship between physical health problems and marital dissatisfaction (Burman and Margolin, 1992), in the current sample, only three individuals with MS and two partners reported marital dissatisfaction as measured by the DAS. In fact, the majority of the couples reported high levels of marital/relationship satisfaction. The high level of relationship satisfaction may in fact be due to a sample bias resulting from the fact that only people with strong relationships might have volunteered to participate in the study. Future studies and efforts need to investigate this bias and minimize this possibility. Further, the relationship between relationship satisfaction and physical abilities must be interpreted cautiously due to the positively skewed satisfaction scores.

Additionally, we had expected that other variables, particularly length of time since receiving a diagnosis of MS and patient's symptom severity, would inversely relate to

levels of optimism. This hypothesis did not receive support from the findings, however. In fact, there were no significant relationships between the aforementioned variables. Because many of the patients were not experiencing debilitating symptoms at the time they were completing the questionnaires, it may not be possible to fully ascertain these relationships. This may be due to a selection bias as well because patients who were not experiencing an exacerbation or worsening of symptoms may have been more willing to participate in the study than were patients who had significant pain or other symptoms. Future research, with data collected at several different intervals in an attempt to track exacerbations and remissions, is clearly necessary. Unfortunately, this is a difficult undertaking due to the unpredictable course of the illness.

### LIMITATIONS

In this section we discuss limitations of the current investigation as well as directions for future research. First, the sample size was small, thereby prohibiting in-depth analyses of the data. Thus, future research needs to examine these trends, using a large sample of patients and partners. Additionally, because of the cross-sectional nature of this study, we were unable to determine causation. Further, no homosexual couples participated in this study, and the sample was fairly homogeneous with respect to ethnicity and income. Moreover, the method of data collection was self-report in nature, and therefore there is a possibility of a response bias. A selection bias may also be present in that all of the couples in this study reported fairly high levels of marital satisfaction and none of the patients reported high levels of physical disability. Future investigations will track relationships observed between variables across time (over 1 year) and among more participants than we included in the present study. Of particular interest will be the observed trend between level of functioning and relationship satisfaction as well as the relationship between depression and optimism and also within couple comparisons.

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