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The Role of Illness Uncertainty on Coping with Fibromyalgia Symptoms

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Abstract

Uncertainty is a common component of the illness experience and can increase the burden of managing chronic illness. The present study examined the role of illness uncertainty in pain coping among 51 women with Fibromyalgia (FM), a chronic pain condition of unknown origin. After completing demographic and illness uncertainty questionnaires, participants underwent 10 to 12 weekly interviews regarding pain, coping difficulty, and coping efficacy. Multilevel analyses indicated that pain elevations in the presence of illness uncertainty predicted increases in coping difficulty. Furthermore, when participants had more difficulty coping, they also had lower levels of coping efficacy. Results are consistent with a model where illness uncertainty accompanied by episodic pain negatively affects coping efficacy, an important resource in adaptation to FM.

Keywords

Illness uncertainty; pain; coping difficulty; coping efficacy; fibromyalgia

Uncertainty is a salient issue for many who have been diagnosed with life-threatening or chronic illnesses (Mast, 1995; Mishel, 1999), particularly for those whose illness itself has no known organic cause. One such prevalent condition is Fibromyalgia (FM). FM has been characterized by the presence of widespread and often unpredictable musculoskeletal pain, tenderness, fatigue, stiffness, and sleep disturbance. However, it has also been associated with numerous psychosocial conditions, such as depression, anxiety, and physical and sexual abuse (Wolfe & Hawley, 1999; Wolfe, Ross, Anderson, Russell, & Hebert, 1995). Not only do FM patients have a greater number of comorbid physical and psychological conditions than many other chronic pain conditions, but they also have more difficulty coping with their condition (Zautra, Hamilton & Burke, 1999). Furthermore, because the syndrome is characterized by multiple symptoms with no known organic basis, FM is difficult to treat (MacFarlane et al., 2001; Wolfe & Hawley, 1999). According to a meta-analysis conducted by Rossy et al. (1999), the optimal treatment for FM consists of a combination of nonpharmacological treatments, such as exercise, education, and cognitive-behavioral therapy and medication management for sleep and pain symptoms. Although these treatments may be helpful in alleviating symptoms of FM, they are not always effective and there is variable resolution of symptoms.

To further our understanding of the difficulties in adjustment for FM patients, we sought to examine a variable that differentiates FM from other rheumatic diseases. Illness uncertainty has been found to be significantly higher in FM compared to OA patients (Reich, Olmsted, & Van Puymbroeck, in press). Illness uncertainty has been described as a cognitive stressor, a

sense of loss of control, and a perception about one's illness that changes over time (Mast, 1995, Weiner & Dodd, 1993). Mishel defines illness uncertainty as "the inability to determine the meaning of illness-related events (that) occurs in situations where the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes because sufficient cues are lacking" (Mishel, 1990, p. 256). FM is characterized by unpredictable symptoms, unknown etiology, and treatments of unimpressive effectiveness. The illness uncertainty that results may be a key risk factor in adjustment to the condition.

Illness uncertainty has been studied in a number of chronic illness populations, including diabetes mellitus (Landis, 1996), Parkinson's disease (Sanders-Dewey, Mullins, & Chaney, 2001), multiple sclerosis (Mullins, Cote, Fuemmeler, Jean, Beatty, & Paul, 2001), and systemic lupus erythematosus (Akkasilpa, Minor, Goldman, Magder, & Petri, 2000). Research has shown that high levels of uncertainty were most often associated with more perceived stress-related hospital events (Mishel, 1984), less hope (Wineman, Schwetz, Goodkin, & Rudick, 1996), more illness intrusiveness (Mullins et al., 2001), and greater emotional distress and mood disturbance, specifically more anxiety, tension, anger, and depression (Landis, 1996; Mast, 1995; McCormick, 2002; Mullins et al., 2001). Mullins et al. (1995) found illness uncertainty to be the strongest predictor of psychological distress in a post-polio syndrome population.

Although the psychosocial and physical effects of illness uncertainty have not previously been studied in FM patients, Akkasilpa and colleagues (2000) examined the association between fibromyalgia tender points and illness uncertainty, in a group of patients with systemic lupus erythematosus with varying numbers of FM tender points. They found that patients with more pain relating to FM tender points had less health-related hardiness or resilience to illness stressors and greater illness uncertainty. In accordance with the effects of illness uncertainty in other chronic illness populations, illness uncertainty would be expected to have a significant impact on adaptation in a FM population as well.

Primary appraisal, such as the appraisal of physical symptoms or perceived difficulty coping with symptoms, is one factor that influences adaptation to illness (Lazarus & Folkman, 1984). Recent studies suggest that patients with FM are more likely to ascribe greater importance to their health conditions than people with rheumatoid arthritis (RA) or osteoarthritis (OA), and to appraise their symptoms as more severe and distressing than other groups (Wolfe & Hawley, 1999). Unpredictable stressors, such as pain or illness uncertainty, may also be appraised as threatening or distressing and may increase the perception that symptoms are difficult to cope with. Another contributor to adjustment is secondary appraisal, one's assessment of his or her own resources to deal with the situation, defined in this paper as coping efficacy (Lazarus & Folkman, 1984). These two types of appraisal are conceptually separable constructs. Therefore, it is possible that one may appraise symptoms as difficult to cope with and at the same time feel efficacious about one's ability to cope with these troubling symptoms. However, due to the significant difficulties in adjustment to FM, it is likely that an appraisal of increased coping difficulty may result in decreased perception that one can adequately cope with the stressor of symptoms and less adaptive coping behavior.

Efficacy expectations have been found to be an important coping resource that predicts successful adjustment among pain populations. Evidence suggests that everyday efficacy appraisals may directly affect pain symptoms and psychological adjustment to chronic pain (Barlow, Cullen, & Rowe, 2002; Lefebvre et al., 1999; Orengo, Wei, Molinari, Hale, & Kunik, 2001). Lorig and colleagues have found that baseline efficacy as well as changes in efficacy predicted future health status, and that self efficacy rather than changes in behavior or other critical variables seem to be the mechanism through which arthritis self management programs

have their effectiveness on improvements in health (Lorig, Gonzalez, & Ritter, 1999; Lorig & Holman, 2003).

Patients with FM seem to have a deficiency in coping efficacy. Akkasilpa and colleagues (2000) found that FM patients generally have less self-efficacy, more depression, and poorer quality of life than in the general population. They have even lower coping efficacy than other populations with chronic pain, such as chronic back, shoulder, and neck pain patients (Mellegard, Grossi, & Soares, 2001). However, in a longitudinal study of FM patients, those with higher levels of coping efficacy at baseline demonstrated better health status and lower levels of disability the following year (Cronan, Serber, & Walen, 2002; Miller & Cronan, 1998). Higher coping efficacy has also been shown to predict lower pain, pain behavior, and impairment in physical activity in FM (Buckelew, Murray, Hewett, Johnson, & Huyser, 1995; Buckelew et al., 1994). Considering the important health benefits that are attainable through coping efficacy, it is an important outcome variable to examine in this population.

FM patients, who are already at increased risk for psychological distress and low coping efficacy relative to other pain patients, may be especially vulnerable to acute or chronic illness-related stresses, such as pain exacerbations or illness uncertainty, respectively. Therefore, it is important to understand how individual differences in illness uncertainty affect adaptation to illness as well as to identify how individual responses to pain lead to differences in coping. Further, we seek to comprehend how appraisals of coping difficulty bolster or reduce appraisals of coping resources, like coping efficacy. Studying the effects of these variables on a weekly basis, allows us to move beyond determining effects of simple individual differences to exploring dynamic interactions of these variables.

Exacerbations in weekly worst pain and a greater average level of worst pain were expected to be associated with increases in difficulty of coping with FM-related symptoms. This is the first study that has examined how the presence of illness uncertainty coupled with exacerbation of pain affects coping difficulty and coping efficacy. The following hypotheses were tested in the present study: 1) Illness uncertainty predicts increased difficulty coping with symptoms, primarily during weeks with greater pain, 2) Illness uncertainty predicts decreased coping efficacy, particularly during weeks with greater pain, and 3) On weeks when difficulty coping with symptoms is high, coping efficacy will be lower. Coping efficacy was also expected to be lower for individuals who more often appraise symptoms as more difficult to cope with.

Method

Participants

The sample consisted of 51 women with physician-confirmed diagnoses of Fibromyalgia. Participants were recruited through flyers placed in physicians' offices and other public locations, physician referral, newspaper ads, senior citizens' groups, arthritis groups, and mass mailings to members of the Arthritis Foundation. To be eligible, participants were restricted from being involved in any health-related litigation. If participants had other pain conditions, they must have endorsed FM as their most problematic illness. Participants also had to have a pain level over the past week that was more than 20 or the mean average pain over the past week and the average pain over the past month was more than 25 on a 0 to 100 scale, where 0 is "no pain" and 100 is "pain as bad as it can be," not currently be involved in any health-related litigation, be living with a romantic partner who was also willing to participate in the study, and be diagnosed after 1988. Of all potential participants who were screened, 39% were excluded from the study based on these exclusion criteria.

All participants were female Arizona residents between the ages of 35 and 69, ($M = 52$, $SD = 7.3$). The majority of participants were Caucasian (96%) and the average income of the sample

was \$50,000–59,999. In terms of education level and employment, 98% completed high school, 36% completed 4 years of college, and 34% were employed. Although all participants were living with a romantic partner at the start of the study, 91% reported being married. All participants had a primary diagnosis of FM and reported having symptoms for an average of 10 years ($SD = 8.5$). Participants had a mean level of 1.5 ($SD = 1.16$) other health conditions besides FM, including rheumatoid arthritis, osteoarthritis, back pain, gout, lupus, tendonitis, osteoporosis, and health conditions not otherwise specified.

Procedure

The data used were obtained from a multiyear project assessing a range of mental and physical health variables in a community-based sample of FM patients in the Phoenix, AZ metropolitan area. The current study made use of data from the initial mailed questionnaire and 10–12 weeks of telephone interviews conducted by trained research assistants. Interviews were scheduled for a regular weekly time and lasted approximately 45 minutes.

Initial interview—Upon receipt of signed consent forms, all participants were mailed an initial questionnaire. The initial questionnaire was picked up at the time of the Initial Visit. All Initial Visits were performed in the participant's home by trained female research assistants and consisted of the completion of study questionnaires, a multiple tender point examination (MTPS), and a range of motion joint exam (Okifuji, Turk, Sinclair, Starz, & Marcus, 1997).

Weekly interviews—After successful completion of the Initial Visit, participants entered the Weekly Interview phase. At this point, all participants were assigned a research assistant trained to perform a standard 45-minute telephone interview. Each participant was interviewed once a week for 10 to 12 weeks. If an interview did not occur at its regularly scheduled time, the interviewer attempted to contact the participant for up to 3 days. After 3 days of no contact, data for that week was considered missing. On average, the number of completed weeks per subject was approximately 9 weeks with an average of 5.8% of weekly data missing.

Measures

Illness uncertainty—Illness uncertainty was assessed using the Mishel Uncertainty in Illness Scale—Community Form that was a part of the initial questionnaire, completed by the participant at home and sent in through the mail. The Mishel Uncertainty in Illness Scale—Community Form (MUIS-C; Mishel, 1981) assesses four components of illness uncertainty: ambiguity, uncertainty, lack of information, and unpredictability. It consists of 23 items asking respondents to rate on a 5-point Likert scale the degree to which they agree or disagree with a variety of uncertainty statements, such as “I don't know what's wrong with me.” The MUIS-C yields a single composite score, with higher scores reflecting greater uncertainty. Previous studies have shown the MUIS-C to be a reliable and valid measure of illness uncertainty across a number of chronic disease states (Bailey & Nielson, 1993; Mullins et al., 2001; Mullins et al., 1995). *Alpha* reliability estimates have been reported as moderate to high for a variety of illness populations (Mishel et al., 1991) and *alpha* was .87 in the present study.

Worst pain—Worst pain was assessed during each weekly interview with the following instruction, “Please choose a number between 0 and 100 that best describes the worst level of pain you have experienced over the past week due to your fibromyalgia. A zero (0) would mean ‘no pain’ and a one hundred (100) would mean ‘pain as bad as it can be.’” This inquiry about weekly worst pain has been validated in previous studies for assessing pain in similar populations (Smith & Zautra, 2002; Zautra, Smith, Affleck, & Tennen, 2001).

Difficulty coping with symptoms—Difficulty coping with symptoms was assessed during each weekly interview by the instruction, “How difficult was this event to cope with?” referring

to when FM symptoms were the worst in the past week. Participants were asked to indicate on a 5-point Likert scale (from 1, *Not difficult* to 5, *Extremely difficult*) how difficult their worst symptoms were to cope with in the past week. Previous support for this question can be found in the coping appraisal literature (Carver, Scheier, & Weintraub, 1989; Lazarus & Folkman, 1984).

Coping efficacy—Two items in the weekly interview were used to assess coping efficacy. The first was, “How satisfied are you with how you coped with your symptoms?” referring to the past week. Participants were asked to indicate on a 5-point Likert scale how satisfied they were with how they coped with their worst symptoms in the past week. The second item was, “If you had similar symptoms again, how certain are you that you would be able to adjust well to its negative aspects?” referring to the past week. Again, participants were asked to indicate on a 5-point Likert scale about how certain they were that they could cope with similar symptoms in the future. The scores of these items were averaged to produce one composite score of coping efficacy, where 1 indicates low coping efficacy and 10 indicates high coping efficacy. These two single items were significantly correlated with each other ($r = .53, p < .01$). Evidence for the validity of these measures of coping efficacy is strong (see Reich & Zautra, 1991; Zautra & Wrabetz, 1991). In order to estimate reliability for this measure, estimate stabilities were conducted across the 10–12 weeks. This yielded an average week-to-week correlation of .39.

Neuroticism—Neuroticism is a psychological trait that is associated with negative affectivity and amplification of perceived symptoms (Smith, Wallston, & Dwyer, 1995; Smith & Zautra, 2002). Neuroticism was included as a control variable to verify that illness uncertainty had effects on coping with fluctuations in pain independent of neuroticism. Neuroticism was assessed in the initial questionnaire using the eight neuroticism items from the John, Donahue, and Kentle (1991) measure of the Big 5 traits. Participants rated their agreement with each statement beginning with “I see myself as someone who...” on a 5-point scale, with 1 representing “*Disagree strongly*,” 3 representing “*Neither agree nor disagree*,” and 5 representing “*Agree strongly*.” Examples of neuroticism items include “Can be moody,” “Can be tense,” and “Gets nervous easily.” Cronbach's α was .81 for neuroticism in the present study.

Data Analysis

The current hypotheses were tested using multilevel modeling of the 10 to 12 weekly observations nested within each of the 51 participants with a total of 516 observations. All multilevel analyses were conducted using the SAS PROC MIXED software (Littell, Milliken, Stroup, & Wolfinger, 1996). The specifications of the current multilevel model were similar to those in Zautra and Smith (2001), and were based on guidelines in Singer (1998). Weekly predictors in the model were partitioned into two components: the average across all of the weeks (Level 2) and deviations from that average for each participant (Level 1) or the centered score for each participant (Singer, 1998). These centered variables were constructed by subtracting each individual's average score on the variable of interest from the individual's weekly score on that variable. Analyzing the data in this way allowed us to examine both within-person and between-person effects. Within-person analyses addressed the question of “when”. For example, **when** weekly pain was high, would difficulty coping with symptoms increase? Between-person equations addressed the question of “who”. They take the following form: Do people **who** have more difficulty coping with symptoms have lower coping efficacy?

There were four level 2 variables that were controlled in this model: age, neuroticism, length of symptomatology, and average level of worst pain. Since there was a significant age range in this sample, age was included as a control variable to reveal any possible age effects on

dependent measure scores. To ensure that the effects of illness uncertainty were not due to the personality variable of neuroticism, it was also included as a control variable. Length of time that the participant has had FM symptoms was controlled for in the case that the effects of illness uncertainty fluctuates over time and may be affected by how long a participant has had symptoms of FM as suggested by previous literature (Mishel, 1999).

Finally, the average level of worst pain was included as a control variable because there was a range of average pain levels across participants. People who have more pain on average may have more difficulty coping with an exacerbation of pain compared to people who have less pain on average. Level of illness uncertainty may also vary depending upon the average level of pain of the individual. In order to control for this potential variation among participants, the interaction term of centered worst pain by average worst pain was included in all multilevel analyses. The interaction term of centered worst pain by average worst pain was initially included in all of the multilevel analyses and was found to not influence any of the results. Hence, this term was excluded from the final analyses. The first equation was initially specified at Level 1 as follows:

$$\text{Level 1: } \text{difficulty coping with symptoms} = \beta_0 + \beta_1 \text{change in worst pain} + r$$

β_0 yields an estimate of the average coping difficulty, β_1 provides a slope estimate of the effects of predictor variables on weekly coping difficulty, and r stands for the within-person residual. Initial models also included the week number in the study to test for any effects of the week of assessment on these prediction equations. The fixed effect of week was non-significant and therefore was dropped from the prediction equation.

Individual differences in the average level of weekly worst pain were also probed through analyses at Level 2, reflected in the averaged scores of weekly worst pain for each participant across the 10 to 12 weekly interviews. In addition to average worst pain, illness uncertainty, age, neuroticism, and length of time that participants had FM symptoms were also added to further examine individual differences. The first Level 2 equation for this model was as follows:

$$\text{Level 2: } \beta_0 = y_{00} + y_{01} \text{illness uncertainty} + y_{02} [\text{age}] + y_{03} [\text{neuroticism}] + y_{04} [\text{timedx}] + u_0$$

A second set of Level 2 equations tested for differences in the slope of β_1 provided in the Level 1 equation reported above. These equations provide for tests of interaction between individual differences on key variables and the influence of Level 1 variables on coping difficulty. For example, the test of individual differences in the relationship between pain and coping difficulty would be designated as:

$$\text{Level 2: } \beta_1 = y_{10} + y_{11} \text{illness uncertainty} + y_{12} [\text{average worst pain}] + u_1$$

In this equation the slope (β_1) designates the estimated relationship between pain and coping difficulty for each participant. This variable is predicted by individual differences in illness uncertainty (γ_{11}) and average worst pain (γ_{12}).

Finally, similar multilevel equations were specified with the addition of average difficulty coping (Level 2) and change in difficulty coping (Level 1) to predict levels of coping efficacy. Other specifications were selected following Singer (1998) to identify the best fitting model of the variances and covariances of the variables under study. Week number, change in pain, and change in coping difficulty did not show significant random effects in the mixed models.

Results

Descriptive statistics are shown in Table 1. Weekly variables were aggregated for each participant across the 10–12 weeks for the descriptive analyses of the sample. A correlation table of all relevant weekly and demographic variables is also provided in Table 2. There were

stronger correlations among the variables that were proposed in the mediational model of this study. Worst pain was moderately correlated with difficulty coping with symptoms ($r = .41$, $p < .01$) and difficulty coping with symptoms was negatively correlated with coping efficacy ($r = -.32$, $p < .01$). By comparison, the correlation between worst pain and coping efficacy was lower than the other correlations in the model ($r = -.12$, $p < .05$).

The findings for the prediction of weekly difficulty coping with symptoms are shown in Table 3. Illness uncertainty did not have a significant direct effect on difficulty coping with symptoms ($p = .38$). Instead, those participants higher in weekly or average worst pain had significantly more difficulty coping with symptoms ($p < .01$). As predicted, the interaction of pain $\times$ illness uncertainty was a significant predictor of difficulty coping with symptoms ($p < .05$), indicating that participants with greater illness uncertainty at the initial assessment showed a steeper increase in the perception that symptoms were difficult to cope with during weeks with high pain exacerbation over and above the direct effect of pain on difficulty coping with symptoms. Table 3 also reports the significant between-subjects variation for weekly difficulty coping with symptoms, as shown in the unstructured random effect of UN (1,1) ($p < .01$), where the effect of the predictors on coping difficulty differed for each subject. The residual was also significant indicating that there was significant variation within persons on difficulty coping with symptoms ($p < .01$).

Next, analyses were conducted to determine whether individual differences in key variables or weekly changes in difficulty coping with symptoms predicted participant ratings of coping efficacy. To test this model, level 1 and level 2 equations were examined using coping efficacy as the criterion variable. The results are presented in Table 4. Contrary to hypothesis, illness uncertainty was not related to coping efficacy directly or in interaction with pain. Furthermore, average levels of worst pain did not predict a significant difference in the level of coping efficacy. However, perceptions that symptoms were more difficult to cope with predicted lower coping efficacy ($p < .01$). In addition, participants with a high average level of coping difficulty predicted lower levels of coping efficacy ($p < .01$). The four control variables used in the prediction of difficulty coping with symptoms and coping efficacy were tested in these analyses and did not influence the Level 1 relationships among any of the variables.

Effect sizes were also computed for all of the significant relationships within the model. According to guidelines outlined in Singer (1998), effect sizes in multilevel modeling were computed using the covariance parameter estimates. By using the covariance parameter estimates for both the within and between-subjects (i.e. residual and the intercept, respectively), the proportion of variation can be explained. For the prediction of difficulty coping with symptoms, weekly worst pain explained 11%, and the interaction of weekly worst pain by illness uncertainty explained an additional 1% of the variance for within-subject variation. Average worst pain explained 33.7% of the between-subject variation of coping difficulty. For the prediction of coping efficacy, weekly variations in coping difficulty explained 6.7% of the within-subject variation of coping efficacy; average coping difficulty explained 20.9% of the between-subject variation of coping efficacy.

A summary of the findings from all the multilevel analyses is displayed in Figure 1 demonstrating how the presence of illness uncertainty relates to increases in the effects of pain in chronic pain conditions, such as FM. The path coefficients noted in the figure are standardized (beta) coefficients for each relationship (Kim & Ferree, 1981). The figure shows that when pain is high for those who have greater illness uncertainty, the perception that symptoms were more difficult to cope with from week to week increases. Furthermore, those who have more pain on average, showed more coping difficulty. When symptoms were perceived to be more difficult to cope with, coping efficacy was lower. A test for mediation was also conducted to confirm that the relations between weekly worst pain and coping efficacy

were fully mediated through difficulty coping with symptoms ($Z = 4.44$, $p < .001$; Sobel, 1982). Therefore, the model posits a set of relationships whereby when pain exacerbations occur in the context of illness uncertainty, the pain may be more difficult to cope with, in turn lowering the level of coping efficacy which is so needed in chronic pain conditions, like FM.

Discussion

This study examined the effects of illness uncertainty on perceived difficulty coping with symptoms and coping efficacy. As expected, exacerbations in weekly pain were related to coping difficulty, in that participants with increased pain had a more difficult time coping with their disease symptoms. Moreover, participants who had higher levels of pain overall reported more coping difficulty, presumably because they had more pain exacerbations over time.

Illness uncertainty played a notable role in defining these relationships. Specifically, participants who had higher levels of illness uncertainty felt that symptoms were even more difficult to cope with when there was an increase in weekly pain compared to participants who had lower levels of illness uncertainty. Illness uncertainty did not have a direct effect on coping difficulty or coping efficacy, suggesting that uncertainty alone may not increase difficulties in coping with FM symptoms. The presence of higher illness uncertainty may best be seen as a moderating variable that makes a person more vulnerable to exacerbations in pain.

With respect to coping efficacy, findings indicated that when people felt that their condition was more difficult to cope with, they had lower levels of coping efficacy. If FM patients more often feel that symptoms are difficult to cope with, it may partially explain previous findings that coping efficacy is low in this hard-to-treat population compared to the general population and compared to other chronic pain patients (Akkasilpa et al., 2000; Mellegard, Grossi, & Soares, 2001).

Taken together, these results support a model of FM for which illness uncertainty heightens the relationship between pain and impaired coping. It is this cycle of response to pain that may explain some of the increased difficulties in coping and lower efficacy expectations of FM compared to other chronic pain conditions. The findings also may help explain increased comorbidity of physical conditions, more depression and anxiety, and greater perceived severity of symptoms in FM as coping efficacy has been found to decrease psychological distress and improve health status (Lorig & Holman, 2003; Zautra & Wrabetz, 1991).

Study limitations place some constraints on the inferences we can draw from the data. One constraint is that illness uncertainty was only measured at one time point. Mishel (1999) suggests that uncertainty is a dynamic perception that changes over time and therefore may fluctuate with varying levels of pain. Another limitation is that all participants self-selected to participate in this study. Further, this study could not probe causal relations among the variables. Weekly worst pain, difficulty coping with symptoms, and coping efficacy were measured in the same interview. Future research may study pain and illness uncertainty within an experimental paradigm to assess the causal relationships between pain, illness uncertainty, and coping. Analyzing daily and within-day electronic diaries, would permit an examination of temporal ordering of these relations from one day to the next that would provide greater evidence of causal relations among the variables.

Despite its limitations, this study advances our thinking about FM. This is the first study to examine the effects of illness uncertainty in FM and the detailed inquiry yielded important data on how people with FM respond to uncertainty. These findings may be especially useful in further developing nonpharmacological interventions for people with FM. In light of the findings of this study, interventions targeted at reducing illness uncertainty may result in decreasing the difficulties that patients with FM have in coping with their condition and

subsequently enhance their coping efficacy. Little work has been done on interventions focusing on directly ameliorating the effects of illness uncertainty for people with FM. Although, the prognosis and course of the condition are unknown, intervention may be able to better prepare patients with FM with appropriate responses for possible symptoms that they may encounter with their condition. Self-management interventions, including educational and cognitive-behavioral techniques, have been studied with FM and have been found to result in improvements in both physical and psychosocial functioning. However, when these approaches were compared to an attention-placebo control, no differences were found (Nezu, Nezu, & Lombardo, 2001; Nicassio et al., 1997; Vlaeyen et al., 1996). This suggests that there is room for improvement in finding an intervention that is superior to attention-placebo for FM patients. Utilizing educational and cognitive-behavioral approaches to help patients better manage the uncertainty of their condition may be an important avenue to pursue.

Another approach to reducing the damaging effects of illness uncertainty in FM would be to teach patients how to better accept uncertainty and unpredictability of their illness (Mishel, 1999). Mindfulness approaches focusing on concepts such as acceptance and living in the moment, such as those of Kabat-Zinn (Kabat-Zinn et al., 1992; Kaplan, Goldenberg, & Galvin-Nadeau, 1993) appear to be promising avenues for improving coping and reducing the negative effects of uncertainty for FM patients. A few studies have examined the effects of mindfulness meditation-based stress reduction for FM and have demonstrated improvements in FM-related and psychosocial symptoms as well as enhanced coping (Goldenberg et al., 1994; Kaplan, Goldenberg, & Galvin-Nadeau, 1993; Weissbecker et al., 2002). Mindfulness interventions develop the ability to recognize negative thoughts, feelings, and sensations, such as pain or appraisals of coping difficulty, as momentary aspects of awareness. Mindfulness interventions also promote greater emotional clarity, allowing FM patients' ability to experience both positive and negative affect, which may reduce the predominant negative emotional consequences of the syndrome. Furthermore, this type of intervention gives FM patients some tools to actively cope by engaging in a practice of pain acceptance about an uncertain condition, where other active coping strategies may not have worked in the past.

This study demonstrated that illness uncertainty influences adaptation to this chronic illness condition. Future research should explore the composition and tolerance of illness uncertainty to determine what predicts individual differences in illness uncertainty. Another avenue of future exploration would be to examine the dynamic nature of illness uncertainty to explore whether or not illness uncertainty varies over time or is dependent on symptom fluctuation or on the length of time since diagnosis. In sum, illness uncertainty adds to the difficulty of coping with pain and other symptoms related to FM, lowering the patient's belief that he or she can cope effectively with the illness. Even though we may not be able to completely resolve the uncertainty that surrounds this condition, through intervention, we may be able to reduce the impact that illness uncertainty has on the lives of people with FM.

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Figure 1. Multilevel regressions predicting weekly difficulty coping with symptoms and weekly coping efficacy.

Table 1
Descriptive Statistics of Key Weekly and Demographic Variables

Variables	M	SD	Range	Skewness	Kurtosis
Within-Person (N = 516)					
Worst Pain	71.32	20.02	3–100 ^d	–0.60	–0.20
Difficulty Coping	3.17	0.99	1–5 ^b	0.04	–0.34
Coping Efficacy	6.81	1.54	2–9 ^c	0.59	0.24
Between-Person (N = 51)					
Illness Uncertainty	2.93	0.55	1.7–4.2 ^d	0.31	–0.28
Age	52.04	7.29	35–69 ^e	0.56	0.04
Neuroticism	3.32	0.76	1.4–4.9 ^f	–0.26	–0.13
Years of Symptomatology	10.85	8.48	1–39	1.67	2.42

Note. The first three variables were taken on a weekly basis for 10–12 weeks. The last four variables were only assessed once.

^a 0 indicates “no pain” and 100 indicates “pain as bad as it can be”.

^b In reference to difficulty coping with symptoms in the last week, 1 indicates “not difficult” and 5 indicates “extremely difficult”.

^c In terms of coping efficacy in relation to symptoms, 1 indicates low coping efficacy and 10 indicates high coping efficacy.

^d 1 indicates low illness uncertainty and 5 indicates high illness uncertainty

^e Age is listed in terms of years. The possible range for the sample was 35–72 years.

^f 1 indicates low neuroticism and 5 indicates high neuroticism.

Table 2
Correlation Matrix of Key Weekly and Demographic Variables

Variables	Illness Uncertainty	Average Coping Difficulty	Average Coping Efficacy
<i>Between-Person Variables (N = 51)</i>			
Illness Uncertainty	---	.176	-.244
Average Worst Pain	.122	.541**	-.125
Average Coping Difficulty	.176	---	-.404**
Age	-.140	-.226	.151
Length of Symptoms	.085	-.184	.070
Neuroticism	.300*	.151	-.323*
<i>Within-Person Variables (N = 516)</i>			
Weekly Worst Pain	.092*	.408**	-.118**
Weekly Coping Difficulty	.105*	---	-.318**

*
 $p < .05$

**
 $p < .01$

Table 3
Multilevel Regressions Predicting Weekly Difficulty Coping with Symptoms

Random Effects					
Covariance Parameter Estimates	Subject ID	B	SE	Z	p
Intercept		0.17	.05	3.45	<.01
Residual	.	0.65	.04	14.90	<.01
Fixed Effects					
Predictor Variables	B	SE	df	t	p
Within-person					
Δ in Worst Pain (ΔWP)	0.01	.003	445	7.34	<.01
Between-person					
Average Worst Pain	0.02	.004	48	4.41	<.01
Centered Illness Uncertainty	0.11	.13	48	0.89	.38
Within × Between-Person					
ΔWP × Centered Illness Uncertainty	0.01	.004	445	2.07	<.05

Note. Control variables, age, neuroticism, length of symptomatology, and average level of worst pain were tested and were nonsignificant.

Table 4
Multilevel Regressions Predicting Weekly Coping Efficacy

Covariance Parameter Estimates	Random Effects			
Intercept Residual	Subject ID	B 0.61 1.53	SE .16 .10	Z 3.77 14.87
p <.01 <.01				
Predictor Variables	B	SE	df	t
p				
Within-person				
Δ in Weekly Difficulty Coping	0.34	.07	444	-4.72
Δ in Worst Pain (ΔWP)	0.01	.004	444	-1.60
Between-person				
Avg. Difficulty Coping	0.80	.26	47	-3.08
Average Worst Pain	-0.01	.01	47	1.06
Centered Illness Uncertainty	0.30	.23	47	-1.34
Within × Between-person				
ΔWP × Centered Illness Uncertainty	0.01	.01	444	-1.02
p				
				<.01
				.11
				<.01
				.30
				.19
				.31

Note. Control variables, age, neuroticism, length of symptomatology, and average level of worst pain were tested and were nonsignificant.