ILLNESS DURATION AND COPING STYLE IN CHRONIC FATIGUE SYNDROME

MOLLY M. BROWN, ABIGAIL A. BROWN, and LEONARD A. JASON
Center for Community Research, DePaul University

Summary

A sample of patients with chronic fatigue syndrome was recruited to assess coping strategies and illness duration. It was hypothesized that adaptive coping strategies would be higher among those with longer illness duration. Those in the longer illness duration group reported higher use of active coping, positive reframing, planning, and acceptance, and lower use of behavioral disengagement than those in the shorter illness duration group. No significant differences were found between the two illness duration groups for physical impairment or symptom severity, but the long duration group revealed a lower percentage of participants who were working than the short duration group. These findings suggest that individuals with longer or shorter duration of the illness have differences in coping styles but not differences in physical impairment or symptom severity.

Chronic fatigue syndrome is an often highly debilitating and long-term illness. Research suggests that illness duration of two years or less is a predictor of recovery from chronic fatigue syndrome (van der Werf, de Vree, Alberts, van der Meer, & Bleijenberg, 2002). However, most patients with this illness continue to meet criteria for longer than two years. In a longitudinal study, Nisenbaum, Jones, Unger, Reyes, and Reeves (2003) found that among a sample of participants with chronic fatigue syndrome, most continued to meet criteria for chronic fatigue syndrome during at least one follow-up assessment over a three-year period. However, the authors found that the number of core chronic fatigue syndrome symptoms as well as other somatic symptoms significantly decreased over time.

In comparing subgroups of individuals with chronic fatigue syndrome based on illness duration, Friedberg, Dechene, McKenzie, and Fontanetta (2000) found that those with an illness duration of 10 years or longer had significantly worse cognitive functioning than those who had chronic fatigue syndrome for seven years or less. However, they found no significant differences between the two groups in terms of severity of somatic complaints or coping style. It is possible that differences in symptoms and coping may not have been detected in Friedberg, et al.’s study because illness duration groups of up to seven years and at least 10 years may not be disparate enough for comparison. It is possible that patients are able to utilize more adaptive coping strategies as they adjust to living with a chronic illness and that a shorter illness duration cutoff is necessary to make these comparisons.

Lipowski (1970) described the process of illness-specific coping as behaviors used to assist in the process of recovery and to compensate for physical limitations. This suggests that coping refers to both overcoming problems brought on by the illness, and enduring other

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1Address correspondence to Molly M. Brown, Center for Community Research, 990 W. Fullerton Ave., Suite 3100, Chicago, IL 60614 or mbrown59@depaul.edu.)
problems. Among individuals with chronic fatigue syndrome, coping style may be related to how quickly they psychologically adapt to the illness after onset. Jason, Fennell, Klein, Fricano, and Halpert (1999) suggest that patients with chronic fatigue syndrome experience an initial “crisis” phase characterized by entering into a state of emotional distress after the initial onset of the illness or during a period of relapse. Those in the crisis phase of the illness are more likely to use maladaptive coping styles than those in other phases of the illness (Reynolds, Brown, & Jason, 2009). However, Reynolds, et al., found no relationship between illness phase and illness duration, in developing this illness phase model, Jason, et al. recognized that patients may move out of the crisis phase and return during a relapse, suggesting that the relationship between illness duration and illness phase is not necessarily linear. Thus, although illness phase may predict the use of particular coping styles, it remains important to explore whether patients improve coping over time regardless of illness phase.

Previous research on coping strategies among individuals with chronic fatigue syndrome has shown, in general, that individuals with this illness are more likely to use coping strategies typically considered to be maladaptive when compared to healthy controls or other illness groups (Ax, Gregg, & Jones, 2001; Creswell & Chalder, 2001). Patients with chronic fatigue syndrome were found to use an uncommon coping strategy, Defensive High Anxious, more often than healthy individuals and those with other chronic illnesses (Creswell & Chalder, 2001). Avoidance coping has also been reported among patients with chronic fatigue syndrome (Ax, et al., 2001). More specifically, Moss-Morris, Petrie, and Weinman (1996) found that people with chronic fatigue syndrome who had negative beliefs about their illness were likely to disengage themselves in stressful situations. Similarly, Heijmans (1998) found that for patients with chronic fatigue syndrome, a sense of illness control was associated more with problem-focused coping strategies than avoidant coping strategies. Wilson, Hickie, Lloyd, Hadzi-Pavlovic, Boughton, Dwyer, et al. (1994) even suggested that coping strategies and illness attitudes are more predictive of illness outcomes than are immunological markers.

However, it is likely that there is variability in coping styles within samples with chronic fatigue syndrome. Moreover, specific symptoms, such as postexertional malaise, must be considered when interpreting coping mechanisms. Individuals with this illness may be more likely to use avoidance because engaging in some activities may, in fact, cause postexertional malaise, a symptom characterized by exacerbation of symptoms following exertion which generally worsen 12 to 48 hours after the mental or physical activity. Thus, patients with chronic fatigue syndrome may preserve their functional ability by engaging in coping strategies that would be interpreted as maladaptive for other groups. Further, some inconsistencies exist as to how people with this illness are differentiated from other groups in terms of coping, as Camacho and Jason (1998) found that patients with chronic fatigue syndrome did not differ in terms of coping strategies compared to people who had recovered from chronic fatigue syndrome and healthy controls. Finally, another study found that participants with chronic fatigue syndrome did not differ in coping compared to a chronically fatigued control group (Nater, Wagner, Solomon, Jones, Unger, Papanicolaou, Reeves, et al., 2006).

Coping style has been implicated in outcomes of overall functioning among patients with other illnesses including rheumatoid arthritis, chronic obstructive pulmonary disease, and psoriasis (Evers, Kraaimaat, Geenen, Jacobs, & Bijlsma, 2003; Scharloo, Kaptein, Weinman, Hazes, Willems, Bergman, et al., 1998). Previous studies have found differences among the coping strategies of chronic fatigue syndrome populations by ethnicity (Njoku, Jason, & Torres-Harding, 2005), sex, and employment status (Jason, Taylor, Kennedy, Jordan, Song, Johnson, et al., 2000). The use of less adaptive coping strategies may be
related to increased disability among individuals with chronic fatigue syndrome (Ax, et al., 2001; Moss-Morris, et al., 1996; Ray, Jefferies, & Weir, 1995), although a causal direction between coping and disability has not been established.

Previous studies of coping among individuals with chronic fatigue syndrome have not explored whether illness duration is predictive of coping style. It is possible that coping skills may develop or change the longer an individual has chronic fatigue syndrome. The present study evaluated coping strategies in a group of participants with chronic fatigue syndrome with a longer illness duration (>2 yr.) and those with a shorter illness duration (≤2 yr.). It was hypothesized that adaptive coping strategies would be utilized more often among those with longer illness duration. The relationship between illness duration and functional status was also explored.

Method

Participants

Participants were recruited for a larger, longitudinal study on non-pharmacological interventions for chronic fatigue syndrome (see Jason, Torres-Harding, Friedberg, Corradi, Njoku, Donalek, et al., 2007). Data for the present study were from the baseline, pretreatment assessment. All participants met the Fukuda, Straus, Hickie, Sharpe, Dobbins, and Komaroff (1994) criteria for chronic fatigue syndrome. Additional requirements for enrollment in the study included that participants be a minimum age of 18, English-speaking, and without physical impairments too severe to interfere with attendance at scheduled sessions (e.g., bedridden or housebound). In cases of ineligibility for enrollment in the study, these individuals were provided with physician and support group referrals. A total of 114 individuals were found to be eligible for the Jason, et al. study and was included in the present investigation.

Procedure

Participants were administered the Structured Clinical Interview for DSM–IV (First, Spitzer, Gibbon, & Williams, 1995) to diagnose any Axis I disorders and rule out exclusionary psychological disorders according to the Fukuda, et al. (1994) criteria. A physician screening and laboratory tests were also conducted to assess the presence of exclusionary medical illnesses (Fukuda, et al., 1994). Once study eligibility criteria were met, participants completed a battery of self-report measures. For additional details regarding study procedures, see Jason, et al. (2007).

Materials

Physical functioning—The Physical Functioning Scale of the Medical Outcomes Study-Short Form-36 (Ware & Sherbourne, 1992) was administered to measure overall physical disability. Scores on the Physical Functioning Scale range from 0 to 100, with higher scores indicating better functioning.

Fatigue—The Fatigue Severity Scale (Krupp, LaRocca, Muir-Nash, & Steinberg, 1989) was used to assess fatigue severity. This inventory consists of 9 items rated on 7-point scales, with severity rated as 1: No fatigue to 7: Very severe fatigue. The final severity score is determined by averaging the nine self-reported scores. The scale items primarily concern the behavioral effects of fatigue, and measure different facets of fatigue including the extent of physical, social, and emotional impairment.

Symptoms—Participants completed the Chronic Fatigue Syndrome Questionnaire (Jason, Ropacki, Santoro, Richman, Heatherly, Taylor, et al., 1997) to collect demographics, illness
duration, and symptom severity data for the eight core Fukuda, et al. (1994) symptoms. Symptom severity scores ranged from 0 to 100, with higher scores indicating more severe symptoms. The above measures are described in more detail in Jason, et al. (2007).

Coping—Coping was measured using the Brief Coping Orientation to Problems Experienced Scale (Carver, 1997). This inventory was derived from the Coping Orientation to Problems Experienced Scale (Carver, Scheier, & Weintraub, 1989) and assesses different means of coping with stress. The Brief Coping Orientation to Problems Experienced Scale includes scale items intended to measure and distinguish between problem-focused coping and emotion-focused coping strategies. A total of 28 items are rated on 4-point scales, with scores ranging from 1: Not engaging in the coping strategy to 4: Engaging in the coping strategy a lot. Fourteen distinct coping strategies are measured, each based on the average of two unique scale items. For each strategy, scores range from 1 to 4, with higher scores indicating more use of that coping strategy. The following scales and reliability coefficients were reported by Carver (1997): Self-Distraction ($\alpha = .71$), Active Coping ($\alpha = .68$), Denial ($\alpha = .54$), Substance Use ($\alpha = .90$), Use of Emotional Support ($\alpha = .71$), Use of Instrumental Support ($\alpha = .64$), Behavioral Disengagement ($\alpha = .65$), Venting ($\alpha = .50$), Positive Reframing ($\alpha = .64$), Planning ($\alpha = .73$), Humor ($\alpha = .73$), Acceptance ($\alpha = .57$), Religion ($\alpha = .82$), and Self-Blame ($\alpha = .69$).

The Substance Use scale was omitted from the analysis because it had the lowest scores for both groups compared to the remaining scales of the Brief Coping Orientation to Problems Experienced Scale. Previous studies have demonstrated that patients with chronic fatigue syndrome often experience physical intolerance to substances such as alcohol due to exacerbation of symptoms (e.g., fatigue, unrefreshing sleep) and most patients voluntarily abstain from substance use (Woolley, Allen, & Wessely, 2004). Therefore, measuring substance use for individuals with chronic fatigue syndrome may not be useful. Moreover, substance use disorders detected during the Structured Clinical Interview for DSM–IV were exclusionary to a diagnosis of chronic fatigue syndrome based on the Fukuda, et al. (1994) criteria.

Analysis

First, reliability statistics (Cronbach’s alpha) were calculated for the 13 brief COPE scales used in this study. Next, participants were placed into one of two illness duration groups based upon reported duration on the Chronic Fatigue Syndrome Questionnaire. The short duration group ($n = 15$) reported chronic fatigue syndrome for less than or equal to 2 yr. The long duration group ($n = 99$) reported chronic fatigue syndrome for longer than 2 yr. This 2-yr illness duration cutoff has been used in previous studies of chronic fatigue syndrome to differentiate between short and long duration (van der Werf, et al., 2002; Nisenbaum, et al., 2003).

Due to the large number of outcome variables in the current study, multivariate analysis of variance (MANOVA) was used to control for potential Type I error. Illness duration was used as the grouping variable for all analyses. One MANOVA included the 13 Brief Coping Orientation to Problems Experienced Scale items as the dependent variables. A second MANOVA was conducted with the following outcome variables: the Physical Functioning scale from the Medical Outcomes Study-Short Form-36, Fatigue Severity Scale score, and reported severity of the eight Fukuda, et al. (1994) symptoms from the Chronic Fatigue Syndrome Questionnaire. Wilks’ lambda was used for interpretation of multivariate tests. Between-group effect sizes were measured using Cohen’s $d$. 

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Results

Demographics
In regards to demographic characteristics, 83.3% of the participants were female \((M \text{ age} = 43.8 \text{ yr., } SD = 11.6)\). Concerning ethnicity, 87.7% of the participants were White, 4.4% were African American, 4.4% were Latino, and 3.5% were Asian American. Regarding marital status, 49.1% of the participants were married or living with someone, 33.3% were single, and 17.6% were either divorced or separated. As for work status, 40.4% of the participants were working or full-time students, and 59.6% were not working or were part-time students. Concerning education, 47.4% of the participants had earned a standard college degree, 21.8% had a graduate or professional degree, 21.1% had partial college, and 9.7% had a high school/GED degree or less.

No significant differences in race, sex, or marital status were found between the two illness duration groups. However, an independent samples \(t\) test revealed a significant difference between the two groups for age \((t_{112} = -3.03, p = .003)\), with the long illness duration group having an average age of approximately ten years older than the short illness duration group. Because age may account for group differences on outcome measures, it was included as a covariate in subsequent multivariate analyses.

The Brief Coping Orientation to Problems Experienced Scale
The following reliability coefficients were found for the 13 Brief Coping Orientation to Problems Experienced Scale scales for the current study: Self Distraction \((\alpha = .60)\), Active Coping \((\alpha = .81)\), Denial \((\alpha = .80)\), Emotional Support \((\alpha = .86)\), Behavioral Disengagement \((\alpha = .61)\), Venting \((\alpha = .64)\), Instrumental Support \((\alpha = .82)\), Positive Reframing \((\alpha = .82)\), Self-blame \((\alpha = .73)\), Planning \((\alpha = .82)\), Humor \((\alpha = .85)\), Acceptance \((\alpha = .72)\), and Religion \((\alpha = .83)\). A statistically significant overall multivariate effect was found for illness duration on the 13 Brief Coping Orientation to Problems Experienced Scale scales \((F_{13,94} = 1.92, p = .04)\). Because a significant multivariate effect was found, univariate effects and effect sizes (Cohen’s \(d\)) were examined next (see Table 1). Significant univariate effects were found for Active Coping, Behavioral Disengagement, Positive Reframing, Planning, and Acceptance. For these significant effects, the long illness duration group reported higher use of Active Coping, Positive Reframing, Planning, and Acceptance, and lower use of Behavioral Disengagement than the short illness duration group. No significant univariate differences were found for Self-distraction, Denial, Emotional Support, Instrumental Support, Venting, Humor, Religion, or Self-blame.

Fatigue and Disability Measures
Measures of physical functioning, fatigue severity, and the eight Fukuda, et al. (1994) symptoms were included as outcomes in a second MANOVA, where a nonsignificant multivariate effect was found \((F_{10,93} = 1.07, p = .40)\). Means, standard deviations, and effect sizes for these outcomes for the short and long illness duration groups are reported in Table 2. No significant univariate differences were found for these outcome measures. In addition, a chi-square analysis revealed a significant difference between the illness duration groups for work status [working vs not working: \(\chi^2(1, N = 114) = 4.97, p = .04\)]. The long illness duration group had a significantly lower percentage of participants who were working (37%) than the short duration group (66.7%).

Discussion
The goal of this study was to examine the differences in coping strategies and physical functioning between chronic fatigue syndrome populations of short illness duration and long
illness duration. The short and long illness duration groups did not significantly differ on measures of physical functioning, fatigue severity, or symptom severity. The results suggest that although patients with chronic fatigue syndrome may display a high level of impairment over time, their coping strategies may improve over the course of their illness. The long illness duration group used adaptive coping strategies such as active coping, positive reframing, planning and acceptance more often than the short illness duration group. Further, those with a long illness duration used behavioral disengagement less often than those with a short illness duration. This suggests that over time, patients with chronic fatigue syndrome show signs of more adaptive coping, regardless of their continuing poor physical functioning.

Results also showed that a smaller percentage of participants with long illness duration was working than those with short illness duration. While declines in work status may be indicative of increased impairment for the long duration group, it may also be that patients learn to accommodate to their limitations, for example, by avoiding overexertion caused by employment. Previous research indicates that patients with chronic fatigue syndrome who use more adaptive coping strategies tend to make accommodations for their illness, such as reducing activity level (Friedberg, et al., 2000), or removing the burden of employment.

These results suggest that in the early stages of the illness, patients may not be prepared to cope in an effective way and are less likely to make accommodations for the illness. Although the less adaptive coping styles observed in the short duration group resembled the patterns of coping found by Reynolds, et al. (2009) in the “crisis” phase group, Reynolds, et al. did not find a significant relationship between illness duration and illness phase. As noted earlier, people with this illness may return to the “crisis” phase during periods of relapse, regardless of how long they have been ill. The present study’s findings suggest that patients show improvements in coping over time independent of illness phase. Taken together, those who have recently become ill with chronic fatigue syndrome, or are experiencing a relapse, may particularly benefit from coping skills training that emphasizes active coping and accommodating to the illness by maintaining an appropriate amount of activity based on individual abilities.

There are several limitations to this study. The short illness duration group was quite small (n = 15) compared to the long illness duration group (n = 99). Future research should seek to study illness duration groups of more comparable size, while still maintaining an appropriate definition of short and long illness duration. The sample used in the present study was fairly ethnically homogeneous, with 87.7% of the participants self-identifying as White. Previous research has demonstrated that chronic fatigue syndrome is highly prevalent among Latino and African-American populations (Jason, et al., 1999), and there is a strong likelihood that coping styles vary among different ethnic groups (Njoku, et al., 2005). Future research should aim for a more ethnically diverse chronic fatigue syndrome population to account for potential differences in coping strategies. A further limitation is the self-reported illness duration used in this study. Some patients with this illness experience an acute illness onset while others develop symptoms gradually over time. As a result, participants in this sample with a gradual onset may have been less precise in reporting how long they have been ill.

This study demonstrated the importance of distinguishing between short and long illness duration populations with regard to coping strategies. Some research has shown that, in general, patients with chronic-fatigue syndrome used less adaptive coping strategies than healthy individuals. However, this does not acknowledge the improvements in coping individuals may make over time. Further, this study suggests that although patients maintain a high level of physical impairment and symptom severity, they are better able to cope with the illness over time. Results from this study have implications for non-pharmacological
interventions focused on coping skills training during the early stages of this illness, and during periods of relapse. Despite physical impairment over time, coping and accommodating to the illness are apparent in patients with chronic fatigue syndrome.

References


Carver CS. If you want to measure coping but your protocol’s too long: consider the brief COPE. International journal of Behavioral Medicine 1997;4:92–100. [PubMed: 16250744]


TABLE 1
Means, Standard Deviations, and Effect Sizes For Coping Outcomes Among Patients With Short Illness Duration (≤2 Yr.) Versus Long Illness Duration (>2 yr.)

<table>
<thead>
<tr>
<th>COPE subscale</th>
<th>Short (n = 15)</th>
<th>Long (n = 99)</th>
<th>F_{1,106}</th>
<th>Effect Size$^b$</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M  SD</td>
<td>M  SD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self distraction</td>
<td>2.57  0.53</td>
<td>2.74  0.93</td>
<td></td>
<td>0.22</td>
</tr>
<tr>
<td>Active coping$^*$</td>
<td>2.60  0.76</td>
<td>3.18  0.80</td>
<td>6.12</td>
<td>0.74</td>
</tr>
<tr>
<td>Denial</td>
<td>1.37  0.55</td>
<td>1.28  0.60</td>
<td></td>
<td>0.16</td>
</tr>
<tr>
<td>Emotional support</td>
<td>2.47  0.94</td>
<td>2.36  0.93</td>
<td></td>
<td>0.12</td>
</tr>
<tr>
<td>Instrumental support</td>
<td>2.33  0.59</td>
<td>2.59  0.97</td>
<td></td>
<td>0.32</td>
</tr>
<tr>
<td>Behavioral disengagement$^*$</td>
<td>1.63  0.95</td>
<td>1.33  0.48</td>
<td>4.68</td>
<td>0.40</td>
</tr>
<tr>
<td>Venting</td>
<td>2.10  0.60</td>
<td>2.09  0.72</td>
<td></td>
<td>0.02</td>
</tr>
<tr>
<td>Positive reframing$^f$</td>
<td>1.70  0.75</td>
<td>2.50  1.02</td>
<td>9.58</td>
<td>0.89</td>
</tr>
<tr>
<td>Planning$^*$</td>
<td>2.57  0.78</td>
<td>3.07  0.93</td>
<td>4.09</td>
<td>0.58</td>
</tr>
<tr>
<td>Humor</td>
<td>1.60  0.63</td>
<td>1.87  0.92</td>
<td></td>
<td>0.34</td>
</tr>
<tr>
<td>Acceptance$^*$</td>
<td>2.43  0.80</td>
<td>2.99  0.82</td>
<td>4.29</td>
<td>0.69</td>
</tr>
<tr>
<td>Religion</td>
<td>2.50  0.89</td>
<td>2.42  1.03</td>
<td></td>
<td>0.08</td>
</tr>
<tr>
<td>Self-blame</td>
<td>1.87  0.99</td>
<td>1.79  0.79</td>
<td></td>
<td>0.09</td>
</tr>
</tbody>
</table>

Note.

$^a$ Age included as covariate in univariate post hoc tests from MANOVA;

$^b$ Cohen’s $d$

$^*$ $p<.05$.

$^f$ $p<.01$.

$^*$ $p<.01$.
<table>
<thead>
<tr>
<th></th>
<th>Short (n = 15)</th>
<th>Long (n = 99)</th>
<th>Effect Size&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue and Disability&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Physical functioning</td>
<td>37.66</td>
<td>47.02</td>
<td>0.43</td>
</tr>
<tr>
<td>Fatigue severity</td>
<td>6.32</td>
<td>6.02</td>
<td>0.44</td>
</tr>
<tr>
<td>Fukuda Symptoms&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sore throat</td>
<td>26.70</td>
<td>24.55</td>
<td>0.08</td>
</tr>
<tr>
<td>Tender/sore lymph</td>
<td>24.66</td>
<td>28.45</td>
<td>0.14</td>
</tr>
<tr>
<td>Muscle pain</td>
<td>55.20</td>
<td>62.97</td>
<td>0.28</td>
</tr>
<tr>
<td>Pain in multiple joints</td>
<td>27.70</td>
<td>49.16</td>
<td>0.59</td>
</tr>
<tr>
<td>Impaired memory &amp; concentration</td>
<td>60.83</td>
<td>64.32</td>
<td>0.15</td>
</tr>
<tr>
<td>Unrefreshing sleep</td>
<td>78.83</td>
<td>79.90</td>
<td>0.06</td>
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<tr>
<td>Postexertional malaise</td>
<td>71.66</td>
<td>75.66</td>
<td>0.19</td>
</tr>
<tr>
<td>Headaches</td>
<td>51.50</td>
<td>53.14</td>
<td>0.05</td>
</tr>
<tr>
<td>Work Status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working (%)&lt;sup&gt;*&lt;/sup&gt;</td>
<td>66.7%</td>
<td>37.0%</td>
<td></td>
</tr>
</tbody>
</table>

Note.

<sup>a</sup> Age included as covariate;

<sup>b</sup> Cohen’s d;

<sup>*</sup> p<.05.