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# Hope and fatigue in chronic illness: The role of perceived stress

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## Abstract

Fatigue is a debilitating symptom of chronic illness that is deleteriously affected by perceived stress, a process particularly relevant to inflammatory disease. Hopefulness, a goal-based motivational construct, may beneficially influence stress and fatigue, yet little research has examined these associations. We assessed the relation between hope and fatigue, and the mediating effect of stress, in individuals with fibromyalgia, arthritis, and inflammatory bowel disease. Covarying age, sex, and pain, stress partially mediated the association between hope and fatigue; those with greater hope reported less stress and consequent fatigue. Therapeutically, bolstering hope may allow proactive management of stressors, resulting in less fatigue.

## Keywords

chronic illness, perceived stress, physical symptoms, protective factors, well-being

For individuals experiencing chronic illness, feelings of stress and fatigue are a common occurrence. In fact, fatigue, which is conceptualized as overwhelming tiredness, exhaustion, and lack of energy, is typically described by patients as one of their most concerning symptoms (Graff et al., 2011). Such symptoms are particularly relevant for individuals experiencing inflammatory diseases; indeed, the linkage between inflammatory processes and fatigue is well established and may be the result of proinflammatory cytokine response (Collado-Hidalgo et al., 2006). As an example, more than 75 percent of individuals with fibromyalgia report sleep disturbances and fatigue and greater levels of stress than controls (McNallen et al., 2013). Similarly, approximately 70 percent of patients with arthritis and 40–70 percent of patients with inflammatory bowel disease (IBD) experience fatigue (Graff et al., 2011;

Hewlett et al., 2011), and perceived stress is a frequent complaint.

For persons with inflammatory chronic illness, such as arthritis, IBD, and fibromyalgia (Blanco et al., 2005; Maes et al., 1999), perceptions of stress are particularly important for symptom control and condition maintenance. Indeed, stress appears to be strongly linked to the inflammation process, through its effect on glucocorticoid receptor resistance in which it fails to regulate the duration or intensity of inflammatory reactions to stress, resulting in

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vulnerability to disease onset and exacerbation of disease symptoms (Cohen et al., 2012). For example, perceived stress is linked to increased pain in patients with fibromyalgia, increased disease activity, fatigue and pain in those with arthritis, and symptom exacerbation and relapse in patients with IBD (Evers et al., 2013; Maunder, 2005; Treharne et al., 2007).

Given the somewhat ubiquitous nature of stress and fatigue in chronic illness, it is surprising that little investigation is directed toward potential intra-individual factors, such as hope, that might exert a beneficial effect on this process. Conceptualized as a cognitive-emotional and motivational characteristic, hope may manifest in both state and trait forms and is composed of two sub-components: agency, or the ability to identify and initiate movement toward a meaningful, personal goal, and pathways, or the ability to enact problem-solving to overcome barriers to goals (Snyder et al., 1991). For individuals with chronic illness, disturbance of such goal orientation, perhaps as a result of functional limitation or social dysfunction, may contribute to greater likelihood of stress and consequent mental and physical fatigue (Hirsch et al., 2011). On the other hand, the ability to maintain appropriate, perhaps adjusted goals, and to continue to problem-solve and strive to overcome barriers toward their attainment, may help to preempt stress and consequent fatigue reactions (Rasmussen et al., 2006).

To test these assumptions, we examined the association between hope and fatigue across three disease samples—arthritis, IBD, and fibromyalgia—and the potential mediating effect of perceived stress. We hypothesized that hope would be negatively associated with perceived stress and fatigue and that stress would mediate the relationship between hope and fatigue, such that those with greater hope would report lower levels of stress and, in turn, less fatigue. Given the potential associations between increased age and fatigue, and between pain and fatigue, and the greater likelihood of females to develop the diseases of our samples, we covaried these factors in all analyses (Zandman-Goddard et al., 2012).

## Method

### Participants and procedure

All studies were approved by an Institutional Review Board, and electronic consent was obtained. Data from all three samples were collected online, via a secure server, with respondents recruited from local, regional, and national organizations and support groups.

The arthritis sample ( $N = 433$ , mean age = 44.42 years, standard deviation ( $SD$ ) = 12.79 years) was primarily female (87%). Comparatively, the fibromyalgia sample ( $N = 419$ , mean age = 47.72 years,  $SD = 13.14$  years) was 79 percent female, and the IBD sample ( $N = 428$ , mean age = 35.62 years,  $SD = 12.18$  years) was 76 percent female.

### Measures

**Hope.** In the fibromyalgia sample, hope was assessed by the Trait Hope Scale (THS) (Snyder et al., 1991), whereas in the arthritis and irritable bowel disease samples, hope was assessed using the State Hope Scale (SHS) (Snyder et al., 1996). The THS is a 12-item measure of dispositional hope (e.g. “My past experiences have prepared me well for my future”), with four filler items; the SHS has six items, and the respondent is encouraged to think of what is going on in their life “in this moment.” Items are scored on a Likert scale, between 1 (definitely false) and 8 (definitely true). Both scales display excellent psychometric properties, including test-retest reliability, and convergent and discriminant validity (Snyder et al., 1991, 1996). In our samples, internal consistency (Cronbach’s alpha) was excellent: fibromyalgia (.89), arthritis (.92), and IBD (.93).

**Stress.** In the fibromyalgia group, we utilized the stress subscale from the Depression, Anxiety and Stress Scale—short form (DASS-21) (Henry and Crawford, 2005), which consists of seven items assessing general psychological stress in the past week (e.g. “I found it difficult to relax.”); items are scored between 0 (did not apply to me at all) and 3 (applied to me very

much, or most of the time). The IBD and arthritis groups completed the 10-item Perceived Stress Scale (PSS) (Cohen and Williamson, 1988), a widely used empirically established index of perceived stress within the past month (e.g. "... how often have you felt difficulties were piling up so high that you could not overcome them?"). Items are scored between 0 (never) and 4 (very often). Cronbach's alpha scores for the fibromyalgia (.85), IBD (.87), and arthritis (.90) samples were good.

**Fatigue.** In the fibromyalgia sample, fatigue was assessed using the vitality subscale from the Short-Form 36 Health Survey Version 2.0 (SF-36v2), which is a four-item general indicator of energy, with excellent psychometric support (Ware et al., 2007). Items (e.g. "How much of the time during the past 4 weeks did you feel worn out?") are scored from 1 (none of the time) to 5 (all of the time). In the IBD and arthritis samples, fatigue was measured with four items; two from the SF-36v2 and two items from the Fatigue Severity Scale (Krupp et al., 1989). Items (e.g. "Fatigue has interfered with my work, family or social life.") were scored on a Likert scale ranging from 0 (none of the time) to 5 (all of the time). Internal consistency was good: IBD (.86), arthritis (.83), and fibromyalgia (.80).

**Pain.** Assessed as a covariate, pain magnitude and interference were measured with the weighted, normed SF-36v2 pain subscale in the fibromyalgia sample (Ware et al., 2007); an example item includes "How much bodily pain have you had in the past 4 weeks?," which was scored from 1 (none) to 6 (very severe). Pain severity in the arthritis sample was measured with one item from the Arthritis Impact Measurement Scales 2 (Meenan et al., 1992), "How would you describe the arthritis pain you usually had?," which was scored on a 0 (none) to 3 (severe) Likert scale. Pain severity in the IBD sample was assessed with one item from the 10-item bowel symptoms subscale of the Inflammatory Bowel Disease Questionnaire (Guyatt et al., 1989), "How often have you been troubled by pain in the abdomen?," which was

scored from 0 (no increase or normal) to 7 (more frequent than ever before).

## Results

### Statistical analyses

All data appeared normally distributed, with no severe outliers. Multivariate parallel mediation analyses were conducted, using the PROCESS macro in SPSS (Hayes, 2013), with 5000 resamples and bias-corrected confidence intervals; coefficients presented are unstandardized. Missing data were resolved via listwise deletion. An additional set of analyses not covarying pain were conducted.

### Bivariate analyses

In the arthritis sample, hope was significantly negatively associated with pain ( $r = -.18, p < .01$ ), perceived stress ( $r = -.64, p < .01$ ), and fatigue ( $r = -.36, p < .01$ ), whereas stress was positively related to pain ( $r = .24, p < .01$ ) and fatigue ( $r = .41, p < .01$ ). Similarly, in the IBD sample, hope was negatively associated with pain ( $r = -.26, p < .01$ ), perceived stress ( $r = -.70, p < .01$ ), and fatigue ( $r = -.51, p < .01$ ), whereas stress was positively related to pain ( $r = .27, p < .01$ ) and fatigue ( $r = .46, p < .01$ ). Finally, in the fibromyalgia sample, hope was negatively associated with pain ( $r = -.17, p < .01$ ), perceived stress ( $r = -.46, p < .01$ ), and fatigue ( $r = -.31, p < .01$ ), whereas stress was positively related to pain ( $r = .28, p < .01$ ) and fatigue ( $r = .38, p < .01$ ).

### Mediation analyses

Across all samples, our results were partially supported; stress was a partial mediator variable (MV) of the association between hope and fatigue. In the arthritis sample, the initial total effect between hope and fatigue ( $c = -.0278, p < .001$ ) was partially reduced, but the direct effect ( $c' = -.0166, p < .001$ ) did not fall out of significance, following the inclusion of the MV of perceived stress, indicating partial mediation.

The total indirect effect ( $ab = -.0112$ ) was also significant; indirect effect coefficients were the following:  $a = -.4718, p < .001$  (hope to stress) and  $b = .0237, p < .001$  (stress to fatigue). In sum, hope was associated with lower levels of perceived stress and, in turn, with less fatigue.

Similarly, in the IBD sample, the initial total effect ( $c = -.0393, p < .001$ ) was partially reduced, but the direct effect ( $c' = -.0293, p < .001$ ) did not fall out of significance, following the inclusion of the MV of perceived stress, indicating partial mediation. The total indirect effect ( $ab = -.0100$ ) was also significant; indirect effect coefficients were the following:  $a = -.5418, p < .001$  and  $b = .0184, p < .01$ .

Finally, in the fibromyalgia sample, the total effect ( $c = -.5178, p < .001$ ) was partially reduced, but the direct effect ( $c' = -.3359, p < .01$ ) did not fall out of significance with inclusion of perceived stress (MV), suggesting partial mediation. The total indirect effect ( $ab = -.1818$ ) was also significant; indirect effect coefficients were the following:  $a = -.1729, p < .001$  and  $b = 1.051, p < .001$ .

For each sample, a parallel set of analyses were conducted but without the covariate of pain. In all cases, partial mediation remained the outcome, without significant change in direction or magnitude of results; thus, these analyses are not discussed further.

## Discussion

In support of our hypotheses, at the bivariate level, we found that both state and trait hopes were associated with less pain, perceived stress, and fatigue, across all samples. Additionally, perceived stress was positively associated with pain and fatigue. At the multivariate level, again across all three of our chronic inflammatory illness samples, perceived stress explained—in part—the association between hope and fatigue; those with higher levels of hope report less stress and, in turn, less fatigue. Our results support previous research indicating the detrimental relationship between stress and fatigue in the context of chronic illness (Evers et al., 2013; Maunder, 2005; Trehanne et al., 2007) and

extend past findings by examining a potential underlying process. It appears that, to the extent that an individual is able to espouse a sense of hope—or their ability to adaptively select meaningful future goals and also identify means of attaining those goals—they may experience less stress and associated fatigue. Whether dispositional or occurring “in the moment,” a sense of hope may promote an adaptive way of thinking about stressful life experiences that allows transcendence or resolution (Hirsch et al., 2011); more specifically, prior consideration of goals and the means by which to attain them may reduce the threat presented by stressors and may also allow more efficient resolution of stressors, thereby reducing mental and physical exertion expended and consequent fatigue.

Despite the strength of our use of multiple disease samples, our results must be interpreted within the context of potential limitations. Our cross-sectional design precludes examination of causality, and bi-directionality is a possibility; however, our premise is based on theory and previous longitudinal findings (Evers et al., 2013), lending support to our model. Across samples, our use of temporally different measures of hope—state versus trait—may seem inconsistent; however, we consider it a strength that effects were found using different measures; future researchers may want to measure both forms of hope, for comprehensiveness. We referred to fibromyalgia as an inflammatory disease, when findings are inconclusive; at least, fibromyalgia is often comorbid with and may have similar etiological mechanisms as the other inflammatory diseases represented by our samples (Blanco et al., 2005). Our primarily White female samples limit generalizability; however, our samples are reflective of the predominance of incidence in females compared to males of fibromyalgia (9:1), arthritis (3:1), and irritable bowel disease (2:1 to 3:1) (Brant and Nguyen, 2008; Yunus, 2001; Zandman-Goddard et al., 2012); yet, future research with more diverse samples is needed to substantiate our findings. Finally, the partial mediation results suggest

that there are other factors besides stress that help to explain the association between hope and fatigue; this may indicate that hope has a beneficial effect on other variables related to chronic illness, and more comprehensive research is needed to better understand its positive effect.

Despite these minimal limits, our findings may have clinical and rehabilitative implications. Previous research indicates that hope can be inculcated, with consequent effects on well-being; similarly, our results imply that degree of hope, whether state or trait, may help to ameliorate stress and consequent fatigue in individuals with some types of chronic diseases. Brief interventions, including strategies from Motivational Interviewing and Problem-Solving Therapy, as well as more simplistic goal identification and attainment exercises, could be implemented in medical settings or accessed online (Britt et al., 2004; Dube et al., 2007). Promotion of hope, via goal-motivated thoughts and behaviors, may allow an individual with chronic illness, as well as their caregivers (Madan and Pakenham, 2013), to see otherwise frustrating barriers and experiences as manageable, thereby reducing expenditure of mental and physical energy.

In sum, our cross-sample findings suggest that—in the context of chronic illness—the ability to identify a personally meaningful goal and work toward its attainment may be related to less perception of stress and consequent fatigue. Hope may allow someone experiencing chronic illness to preemptively consider goal-attainment within the constraints of their symptoms and make advance plans to overcome barriers; having such a “blueprint” may allow individuals with chronic illness to more successfully navigate stressors, resulting in less stress and less effort expended to resolve stressors and, ultimately, in less fatigue. Given the prominent role of stress and fatigue in inflammatory conditions such as arthritis, IBD, and fibromyalgia, our results are an important first step in understanding underlying processes that may also be the target for future interventions aimed at improving quality of life.

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