
Article:
Hirsch, J.K. and Sirois, F.M. (2014) Hope and fatigue in chronic illness: The role of perceived stress. Journal of Health Psychology. ISSN 1461-7277

https://doi.org/10.1177/1359105314527142

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Please cite as:

Hirsch, J. K., & Sirois, F. M. (2014). Hope and fatigue in chronic illness: The role of perceived stress. *Journal of Health Psychology*. doi:10.1177/1359105314527142

Hope and Fatigue in Chronic Illness: The Role of Perceived Stress

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Keywords: Hope; Stress; Fatigue; Chronic Illness; Arthritis; Inflammatory Bowel Disease; Fibromyalgia

ABSTRACT

Stress and fatigue are interrelated symptoms of chronic illness, and are particularly relevant to inflammatory diseases. Little research, however, has examined potential protective characteristics, such as hopefulness, that may beneficially affect symptomology. We assessed the association between hope and fatigue, and the mediating effect of stress, in individuals with fibromyalgia, arthritis and inflammatory bowel disease. In analyses covarying age and sex, distress partially mediated the association between hope and fatigue; those with greater hope reported less distress and, in turn, less fatigue. Therapeutically bolstering hope may allow those experiencing chronic illness to proactively manage stressors, resulting in less energy expenditure.

Hope and Fatigue in Chronic Illness: The Role of Perceived Stress

For individuals experiencing chronic illness, feelings of distress 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). Further, distress and fatigue appear to be interrelated, and often co-occur in the context of chronic illness.

Such symptoms are particularly relevant for individuals experiencing inflammatory diseases; as an example, more than 75% of individuals with fibromyalgia report sleep disturbances and fatigue, and greater levels of stress than controls (McNallen, McCain, Elswick, Menzies, & Leszczyszyn, 2013). Similarly, approximately 70% of patients with arthritis and 40-70% of patients with inflammatory bowel disease experience fatigue (Graff et al., 2011; Hewlett et al., 2011), and self-reported distress is a frequent complaint.

For persons with inflammatory chronic illness, such as arthritis, inflammatory bowel disease (IBD) and fibromyalgia, 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 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 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 hopefulness, 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 form, and is comprised 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 distress and consequent mental and physical fatigue (Hirsch, Sirois, & Lyness, 2011). On the other hand, the ability to maintain appropriate, perhaps adjusted goals, and to continue to problem-solve strive to overcome barriers toward their attainment, may help to preempt stress and consequent fatigue reactions (Rasmussen, Wrosch, Scheier, & Carver, 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 hopefulness 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.

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, SD=12.79) was primarily female (87%). Comparatively, the fibromyalgia sample (*N*=419, Mean age =47.72, SD=13.14) was 79 percent female, and the IBD sample (*N*=428, Mean age=35.62, SD=12.18) 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”); the SHS has 6 items, and the respondent is

encouraged to think of what is going on in their life "in this moment." Both scales display excellent psychometric properties, including test-retest reliability, and convergent and discriminant validity (Snyder et al., 1991; Snyder et al., 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 & Crawford, 2005), which consists of 7 items assessing general psychological distress in the past week. Cronbach's alpha for the fibromyalgia sample was good (.85). The IBD and arthritis groups completed the 10-item Perceived Stress Scale (PSS) (Cohen & Williamson, 1988), a widely used empirically established index of perceived stress within the past month. Cronbach alphas for the IBD (.87) and arthritis (.90) samples were good.

Fatigue. In the fibromyalgia sample, fatigue was assessed using the vitality subscale from the SF-36v2, which is a weighted, normed 4-item general indicator of energy, with excellent psychometric support (Ware, 2008); this subscale was reverse-scored so that higher scores indicate fatigue. In the IBD and arthritis samples, fatigue was measured with 4 items; two from the SF-36v2 and two items from the Fatigue Severity Scale (Krupp, LaRocca, Muir-Nash, & Steinberg, 1989). Items were scored on a Likert scale ranging from "none of the time" to "all of the time," assessing fatigue manifestation and interference. Internal consistency for the IBD (.86) and arthritis (.83) samples was good.

Pain. Assessed as a covariate, pain magnitude and interference was measured with the weighted, normed SF-36v2 pain subscale in the fibromyalgia sample (Ware, 2008); pain severity in the arthritis sample was measured with one item from the Arthritis Impact Measurement Scales 2 (Meenan, Mason, Anderson, Guccione, & Kazis, 1992); 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).

Statistical Analyses:

Multivariate parallel mediation analyses were conducted, using the PROCESS macro in SPSS (Hayes, 2013), which employs bootstrap resampling to calculate indirect effects, can be used with non-normally distributed data, and allows for indirect effects without the presence of direct effects. Mediation analyses can produce five different results: (i) total effect (*c*); (ii) direct effect (*c′*); (iii) *indirect only effect*, whereby *ab* is significant, but *c* and *c′* are not significant; (iv) *partial mediation*, whereby there is a decrease from *c* to *c′* and *c′* remains significant, and (v) *full mediation*, whereby there is a decrease from *c* to *c′* and *c′* falls out of significance (Preacher & Hayes, 2004).

Results

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 (MV) of the association between hope and fatigue. In the arthritis sample, the initial total effect (*c*; -.0278; p=.0000) was partially reduced, but the direct effect (*c'*; -.0166, p=.0006) 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, 95% CI = [-.02, -.01], ; indirect effect coefficients were: a = -.4718, p<.000, and b = .0237, p<.000. In sum, hopefulness 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*=.0000) was partially reduced, but the direct effect (*c'*; -.0293, *p*=.0000) 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, 95% CI = [-.02, -.00]; indirect effect coefficients were: *a* = -.5418, p<.000, and *b* = .0184, p<.01.

Finally, in the fibromyalgia sample, the total effect (*c*; -.5178; *p*=.0000) was partially reduced, but the direct effect (*c'*; -.3359, *p*=.0038) did not fall out of significance with inclusion of perceived stress (MV), suggesting partial mediation. The total indirect effect (*ab*; -.1818) was also significant, 95% CI = [-.30, -.08]; indirect effect coefficients were: a = -.1729, p<.000, and b = 1.051, p<.000.

Discussion

In support of our hypotheses, at the bivariate level, we found that both state and trait hope 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 distress 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; Treharne 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 hopefulness – or, their ability to adaptively select meaningful future goals and also identify means of attaining those goals – they may experience less distress and associated fatigue. Whether dispositional or occurring "in the moment," a sense of hopefulness 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. Our primarily White female samples limit generalizability; 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 hopefulness can be inculcated, with consequent effects on well-being; similarly, our results imply that degree of hopefulness, whether state or trait, may help to ameliorate distress and consequent fatigue in individuals with some types of chronic disease. 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, Hudson, & Blampied, 2004; Dube, Lapierre, Bouffard, & Alain, 2007). Promotion of hope, via goal-motivated thoughts and behaviors, may allow an individual with chronic illness 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. Hopefulness 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 distress 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, inflammatory bowel disease 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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