A combination of illness invalidation from the work environment and helplessness is associated with embitterment in patients with FM

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Abstract

Objectives. The aim of this study in employed people with FM was to test the hypothesis that embitterment is a function of the joint experience of invalidation from the work environment and helplessness regarding one’s illness.

Methods. Sixty-four full-time (36%) or part-time (64%) employed patients with FM (60 females, mean age 45 years) completed the Illness Invalidation Inventory (3*I) to assess work-related discounting and lack of understanding, the Illness Cognition Questionnaire (ICQ) to assess helplessness and the Bern Embitterment Inventory (BEI) to assess embitterment. Hierarchical regression analysis was performed.

Results. Sixteen percent of the participants experienced embitterment levels in the clinical range. The interaction or combination of discounting and helplessness (P = 0.02) and the combination of lack of understanding and helplessness (P = 0.04) were associated with greater embitterment.

Conclusions. The construct of embitterment has substantial face validity and may result from a combination of invalidation and helplessness. Whereas helplessness is a common target of cognitive-behavioural therapy, evidence-based interventions to redress invalidation and embitterment are needed. It is possible, however, to target invalidation by educating people in the work environment about the consequences of FM and patients’ valid needs for work that is manageable, given each patient’s specific health-related limitations.

Key words: fibromyalgia, work, workload, psychological adaptation, embitterment, resentment, invalidation, helplessness.

Introduction

FM is characterized by chronic widespread pain and the presence of several other symptoms such as fatigue, unrefreshed waking and cognitive symptoms [1]. These symptoms limit patients’ ability to work, increases their probability of work loss and sickness absence, and yields adverse social and economic consequences for patients, employers and society at large [2–4]. It is generally considered important to support patients with rheumatic diseases in their attempts to remain involved in the workforce [5]. Supporting patients in dealing with their interpersonal and emotional problems is critical in this process [6, 7], and one interpersonal, mental state that may hinder people’s ability to work productively is a construct that has been termed embitterment. This reaction typically occurs in response to critical social events that are normal, but not everyday, such as conflicts at work [8].

Both clinical and vocational professionals regularly encounter patients who view themselves as victims of external factors, have difficulty coping, experience a sense of resentment and injustice (e.g. with respect to employers or social agencies) and tend to resist help offered [9]. This state of embitterment appears to emerge as a psychological response when patients feel both invalidated and
invalidation from the work environment and helplessness regarding one’s illness.

**Patients and methods**

**Patients**

Research participants were 64 patients with FM. Inclusion criteria were being employed, at least 18 years of age and diagnosed by a rheumatologist according to the 1990 classification criteria of FM [18]. Patients with FM of the University Medical Center Utrecht and the Diakonessenhuis Utrecht, The Netherlands, were recruited to participate in a questionnaire study. Rheumatologists sent an information sheet and consent form to eligible patients, and consenting patients received a packet of questionnaires. Of 425 patients who were contacted, 201 (47%) patients responded. Of them, 167 (83%) patients provided complete data. For the present study, we analysed the data of 64 FM patients who were employed. Table 1 presents the demographic characteristics of the patients. The study was approved by the medical ethics committee of the University Medical Center Utrecht.

**Instruments**

Invalidation was measured using the work environment scale of the Illness Invalidation Inventory (3*I) [17]. This inventory includes items assessing discounting (five items; e.g. people at work think I can work more than I do) and lack of understanding (three reversed items; e.g. people at work understand the consequences of my health problems or illness). Participants indicated on a 5-point scale ranging from 1 (never) to 5 (very often) how often during the past year people in their work environment reacted to them in the described way. Cronbach’s α for discounting (α = 0.88) and lack of understanding (α = 0.74) were good.

Invalidation can range from 1 to 5, helplessness from 1 to 4 and embitterment from 0 to 4.

**Statistical analysis**

The analyses were performed with SPSS for Windows 16.0. Significance level was set at P < 0.05 (two-tailed). The score distribution of all variables was normal.

**TABLE 1** Characteristics of patients (n = 64)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value (S.D.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender: female, n (%)</td>
<td>60 (94)</td>
</tr>
<tr>
<td>Age, mean (s.d.), years</td>
<td>45.0 (11.3)</td>
</tr>
<tr>
<td>Marital status, n (%)</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>9 (14)</td>
</tr>
<tr>
<td>Married/partnered</td>
<td>48 (75)</td>
</tr>
<tr>
<td>Divorced</td>
<td>5 (6)</td>
</tr>
<tr>
<td>Widowed</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Education level, n (%)</td>
<td></td>
</tr>
<tr>
<td>Primary</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Secondary</td>
<td>43 (67)</td>
</tr>
<tr>
<td>Tertiary</td>
<td>19 (30)</td>
</tr>
<tr>
<td>Years with symptoms, mean (s.d.)</td>
<td>12.3 (8.8)</td>
</tr>
<tr>
<td>Years since diagnosis, mean (s.d.)</td>
<td>4.5 (5.7)</td>
</tr>
<tr>
<td>Employment status, n (%)</td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>23 (36)</td>
</tr>
<tr>
<td>Part-time</td>
<td>41 (64)</td>
</tr>
<tr>
<td>Invalidation, mean (s.d.)</td>
<td></td>
</tr>
<tr>
<td>Discounting</td>
<td>2.4 (0.9)</td>
</tr>
<tr>
<td>Lack of understanding</td>
<td>2.8 (0.8)</td>
</tr>
<tr>
<td>Helplessness, mean (s.d.)</td>
<td>2.1 (0.6)</td>
</tr>
<tr>
<td>Embitterment, mean (s.d.)</td>
<td>1.3 (0.9)</td>
</tr>
</tbody>
</table>

In the present study, embitterment was analysed as a dependent variable. Invalidation as well as helplessness are prompted by the nature of FM. The features of FM are less visible than those of other rheumatic diseases. Invalidation is provoked by the relative invisibility of symptoms such as pain, stiffness and fatigue. Moreover, more in the case of FM than in other rheumatic diseases, FM is characterized by lack of pathological evidence and difficulty in assessing patients’ health. Colleagues and employers may, for example, deny the seriousness of FM, fail to understand symptom fluctuations or think that the patient should have a tougher attitude [6, 13]. The symptoms of FM fluctuate independently of a known pathological process and there in no effective pharmacological treatment against these symptoms. Helplessness is typically provoked by the uncontrollable and unpredictable nature of symptoms as detailed in learned helpless-
The percentage of patients experiencing high embitterment was examined; the cut-off value was set at 2.2. This value is proposed by the creators of the BEI as a preliminary criterion to differentiate between people who may and may not need clinical attention because of their embitterment [12]. The percentage of highly embittered patients was compared with the percentages of high scorers in two other groups that filled out the Dutch translation of the BEI: working patients with RA and people from the general population. Before analysis we tested whether gender, age, marital status (married/partnered vs not married/partnered), education level, years with symptoms, years since diagnosis and employment status were correlated with embitterment, but none of these potential covariates was (all $P > 0.25$). To test our hypothesis that the combination of invalidation and helplessness predicts embitterment, we computed zero-order correlations and performed two hierarchical regression analyses for discounting and lack of understanding, i.e. the two components of invalidation. After centring of the invalidation and helplessness variables [21], in Block 1, helplessness and invalidation were entered, and in Block 2, the helplessness $\times$ invalidation interaction was entered. To interpret significant interactions, regression lines for individuals with low ($-1$ S.D.) and high ($+1$ S.D.) levels of invalidation were plotted for low ($-1$ S.D.) and high ($+1$ S.D.) levels of helplessness [22]. The magnitude of the effect of invalidation for low and high values of helplessness was indicated with Cohen’s $d$ effect sizes, with values of 0.20, 0.50 and 0.80 representing small, medium and large effects, respectively [23].

Results

Descriptives

The means of discounting, lack of understanding, helplessness and embitterment are shown at the bottom of Table 1. Sixteen percent of the patients experienced embitterment levels above the specified cut-off. This percentage is high as compared with two other groups who filled out the Dutch translation of the BEI. Using the specified cut-off value of 2.2 as a criterion [12], 3% of 30 working patients with RA and 8% of 159 research participants from the general population experience embitterment (David Blom, Utrecht University, unpublished work).

Correlations

The correlation between invalidation and helplessness was modest: $r(62) = 0.38$ ($P < 0.01$), and lack of understanding did not correlate significantly with helplessness: $r(62) = 0.15$ ($P = 0.23$). As hypothesized, the two dimensions of invalidation as well as helplessness were moderately to strongly associated with embitterment. The correlations of discounting, lack of understanding and helplessness with embitterment were $r(62) = 0.47$ ($P < 0.001$), $r(62) = 0.28$ ($P = 0.03$) and $r(64) = 0.56$ ($P < 0.001$), respectively.

Multiple regression analyses

The results of the regression analyses predicting embitterment from the invalidation dimensions (discounting and lack of understanding), helplessness and their interaction are shown in Table 2. In Block 1, more embitterment was shown to be independently predicted by more discounting ($t = 2.72, P = 0.009$) and by more helplessness ($t = 3.77, P < 0.001$) in the regression with discounting and—not significantly—by more lack of understanding ($t = 1.82, P = 0.07$) and more helplessness ($t = 5.02, P < 0.001$) in the regression with lack of understanding. In Block 2, the interaction of discounting and helplessness ($t = 2.33, P = 0.02$) and the interaction of lack of understanding and helplessness ($t = 2.05, P = 0.04$) predicted a significant proportion of individual differences in embitterment. Fig. 1 shows these interactions. At low levels of helplessness (1 S.D. below the mean), a small difference in embitterment ($d = 0.28$) was observed between people low and high on discounting, whereas at high levels of

<table>
<thead>
<tr>
<th>Predictor variable</th>
<th>$b$ (s.e.)</th>
<th>$\beta$</th>
<th>Adj. $R^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discounting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Block 1</td>
<td></td>
<td></td>
<td>0.35***</td>
</tr>
<tr>
<td>Discounting</td>
<td>0.33 (0.12)</td>
<td>0.30**</td>
<td></td>
</tr>
<tr>
<td>Helplessness</td>
<td>0.66 (0.17)</td>
<td>0.42***</td>
<td></td>
</tr>
<tr>
<td>Block 2</td>
<td></td>
<td></td>
<td>0.39*</td>
</tr>
<tr>
<td>Discounting $\times$ helplessness</td>
<td>0.36 (0.15)</td>
<td>0.24*</td>
<td></td>
</tr>
<tr>
<td>Lack of understanding</td>
<td></td>
<td></td>
<td>0.30***</td>
</tr>
<tr>
<td>Block 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of understanding</td>
<td>0.24 (0.13)</td>
<td>0.20</td>
<td></td>
</tr>
<tr>
<td>Helplessness</td>
<td>0.79 (0.17)</td>
<td>0.51***</td>
<td></td>
</tr>
<tr>
<td>Block 2</td>
<td></td>
<td></td>
<td>0.34*</td>
</tr>
<tr>
<td>Lack of understanding $\times$ helplessness</td>
<td>0.35 (0.17)</td>
<td>0.22*</td>
<td></td>
</tr>
</tbody>
</table>

Adj. $R^2$ with significance levels of $F$-change. *$P < 0.05$, **$P < 0.01$, ***$P < 0.001$. Adj. $R^2$: adjusted $R^2$. 

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TABLE 2 Hierarchical regression analyses predicting embitterment in patients with FM from invalidation (discounting on top, lack of understanding on bottom), helplessness and their interaction.
helplessness (1 s.d. above the mean) the difference between patients low and high on discounting was large ($d = 1.13$) (Fig. 1a). Similarly, at low levels of helplessness, the difference in embitterment between people low and high on lack of understanding was trivial ($d = 0.09$), whereas at high levels of helplessness the difference between patients low and high on lack of understanding was large ($d = 0.81$) (Fig. 1b). Thus the combination of high invalidation and high helplessness was predictive of high embitterment.

**Discussion**

Among patients with FM, invalidation from the work environment, helplessness, and especially the combination of invalidation and helplessness were independently associated with greater embitterment. Unique features of our study are that it concerned the actual experience of patients who are employed and that psychosocial rather than functional problems in the work situation were studied. Although our study indicates that the combination of work-related invalidation and general helplessness are potentially harmful, leading to embittered patients, the cross-sectional design prohibits explicit conclusions about temporal or causal relations of invalidation and helplessness with embitterment.

The occurrence of helplessness in patients with FM may be explained by FM being shrouded in uncertainty regarding its pathological substrate, prognosis and treatment. The invalidation experiences may be due to FM being difficult to validate using laboratory findings and visual signs of physical deformity [17, 24]. The lack of evidence for the genuineness of symptoms and reduced work ability enhances the potential for stigmatization of FM [25, 26].

Our main hypothesis about the possible determinants of embitterment was supported. Among patients with FM, the combination of illness invalidation and helplessness is associated with embitterment. The concept of moral judgements may be important for understanding this finding [27]. Invalidation, particularly in the context of work and disability benefits, questions the credibility of patients and casts a shadow over their personal moral attitudes [25]. Embitterment, then, may result from the perceived threat to the patient’s moral integrity caused by feelings of invalidation and helplessness. The embittered patient tries to secure this integrity by applying a rigid view of right and wrong; the self is perceived as an innocent victim, whereas wrongdoers such as employers or colleagues are deemed morally wrong. Also, there often is an ongoing effort to convince others of the magnitude of the inflicted injustice [9–12]. Our findings suggest that embitterment is present in a proportion of employed patients with FM, and that this embitterment especially occurs when both helplessness and work invalidation are high.

Either invalidation or helplessness can weaken the patients’ ability to overcome work-related challenges such as managing working conditions, communicating impairments, requesting and receiving modifications or help, and solving interpersonal and emotional difficulties [6, 28–30]. However, the difficulties are particularly acute when work invalidation combines with general helplessness to yield the embittered employee: the embittered patient’s tendency or urge to cling to his or her sense of victimhood interferes with actively managing working conditions [12];
their resentment and ongoing demand for support may impair interpersonal support and communication [9]; and the cognitive intrusions and ruminations of past injustices can increase their fatigue and cause problems in memory and concentration, which are major risk factors for work disability [9, 31, 32]. Furthermore, embitterment typically shows a progressive increase over time [9]. Embitterment can be revealed in interviews and with assessment instruments [12, 31]. In order to prevent the potential deleterious consequences of embitterment, it is important that health professionals and vocational counsellors recognize and act upon arising embitterment in its early stages.

Whereas helplessness is a common therapeutic target in cognitive–behavioural therapy, evidence-based interventions to redress invalidation and embitterment are needed. One could try to target invalidation by reducing the patients’ negative appraisal of the work environment and by educating the work environment about the consequences of rheumatic illnesses and patients’ valid needs for work that is manageable, given each patient’s specific health-related limitations. Furthermore, both invalidation and helplessness may be targeted by improving patients’ knowledge (e.g. of legal issues and options for disabled employers), self-awareness (e.g. of work-related disabilities) and communication skills (e.g. disclosing one’s disabilities and requesting help) within the employment setting [16, 33]. Some suggestions for reducing embitterment have also been proposed. Interventions might deal with distorted thoughts, for example, by teaching patients to detach from ongoing ruminations about past injustices and to adopt different perspectives on such experiences [8, 34–38]. Future research should test these ideas for embittered employees with chronic pain and other health problems.

Some study limitations should be considered when interpreting the results. First, the cross-sectional design provides no insight into the temporal or causal relations among invalidation, helplessness and embitterment. It is possible that embitterment not only follows from invalidation and helplessness, but also strengthens these experiences through preoccupation with injustice and one’s state as a victim. However, the modest association between invalidation and helplessness may indicate that helplessness and invalidation contribute to the development of embitterment rather than vice versa. Secondly, our findings apply to employed patients with FM. Confirmation of the model in other groups will likely depend on the prevalence of helplessness, invalidation and embitterment, which might be relatively high in syndromes with inherent invisibility of symptoms combined with the absence of clear pathological evidence and observable deformity, such as chronic fatigue syndrome, irritable bowel syndrome, chronic whiplash syndrome and some psychiatric disorders. Thirdly, the response rate of 48% may indicate a self-selection bias favouring inclusion of patients with higher or lower scores on embitterment, but such a bias will unlikely have influenced the hypothesized association of combined helplessness and invalidation with embitterment. Fourth, the sample size was relatively small for our regression model with three predictors. With the sample size of 64 and three predictors in the regression model, an effect size ($\beta^2$) of 0.19 could be examined ($\alpha = 0.05$, $1 - \beta = 0.80$), which is in between a moderate ($\beta^2 = 0.15$) and large ($\beta^2 = 0.35$) effect size [39]. Fifthly, to be able to assess experiences of patients we relied on self-report measures. Future studies should have longitudinal and experimental designs, address potential confounders such as depression and illness cognitions and include objective outcomes such as work disability and unemployment rates to replicate and extend the present findings, and to gain insight into the initiation, mediation and perpetuation of embitterment in employed patients with FM.

To conclude, the construct of embitterment has substantial face validity, and its relevance to employee health and productivity is provocative. Clinicians working in occupational health recognize embitterment as a prevalent and heavy burden to both the patient and work environment [9], and knowledge of the conceptual underpinnings of embitterment can direct efforts to reduce it. Whereas helplessness, invalidation and embitterment could be therapeutically targeted in cognitive–behavioural therapy, another approach is to target invalidation by educating people in the work environment about the consequences of FM and about patients’ valid needs for work that is manageable, given each patient’s specific health-related limitations.

### Acknowledgements

We are very grateful to the research participants, Paulien Vermaas and Miranda de Jong, for their advice.

**Funding:** The work was supported by the Dutch Arthritis Association (grant number DAA 09-1-401).

**Disclosure statement:** The authors have declared no conflicts of interest.

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