Long-term sickness absence among patients with chronic fatigue syndrome

Ann Kristin Knudsen, Max Henderson, Samuel B. Harvey* and Trudie Chalder*

Summary
Chronic fatigue syndrome is associated with high levels of occupational disability. Consecutive out-patients at a chronic fatigue syndrome treatment service were studied for associations between occupational status, symptom severity and cognitive and behavioural responses to symptoms. All patients had high symptom levels; however, those on long-term sickness absence had significantly more physical fatigue (β=0.098, P<0.05) and worse sleep (β=0.075, P<0.05). Patients with long-term sickness absence also demonstrated more embarrassment avoidance cognitions (β=0.086, P<0.05) and avoidance resting behavioural responses (β=0.078, P<0.05). Identifying and addressing avoidance behaviours and cognitions regarding embarrassment in interventions may enhance the chances of individuals returning to work.

Declaration of interest
T.C. is an author of self-help books on chronic fatigue.

The level of disability associated with chronic fatigue syndrome (CFS) is often high and the prognosis and occupational outcomes are poor.1 Poor occupational outcomes are seen in many chronic disorders, although the associations between disease severity and work-related function are often weak. Although previous research has suggested an association between the level of physical functioning and risk of long-term sickness absence among fatigued employees,2 other factors including illness beliefs, sleep disturbance, comorbid psychiatric symptoms and attributional style may also be important.1,3–5

The aim of this study was to examine clinical factors associated with long-term sickness absence in patients with CFS. We hypothesised that both symptom severity and cognitive and behavioural responses would be associated with poor occupational outcome.

Method
Consecutive patients entering an out-patient treatment unit for CFS were recruited for this study. All patients were diagnosed with CFS according to the Oxford criteria6 following detailed clinical examination and investigations. The information used in this study was collected prior to any intervention.

Patients self-reported their current work status. Those describing themselves as in full-time, part-time or in casual work, or as students, were classified as ‘at work’. Those on sick leave for longer than 3 months or permanently sick or disabled were classified as ‘long-term sickness absence’.

Patients were asked about the number of symptoms they were experiencing from a list of nine commonly reported by patients with CFS (muscle pain, joint pain, tender neck/armpit glands, un-refreshing sleep, poor memory, headaches, sore throat, malaise for 24 hours or more after exertion, and poor concentration). The number of psychiatric symptoms was assessed by the Revised Clinical Interview Schedule (CISR).7 As fatigue and psychiatric disorder commonly co-occur,4 fatigue symptoms in the CISR were omitted. The level of fatigue was measured by the Chalder Fatigue Scale.9 This measures physical and mental fatigue producing a total score between 0 and 11. The Jenkins Sleep Scale was used to assess sleep problems. The responses are given on a six-point frequency scale (0–5), giving a total score from 0 to 20.10

The Cognitive and Behavioural Responses Questionnaire (CBRQ) is a new scale designed to assess patients’ cognitive and behavioural responses to symptoms.11 It has been validated on 230 patients with CFS (further details available from T.C. on request) and has been used in patients with multiple sclerosis.11

Data were available for 257 consecutive out-patients meeting diagnostic criteria for CFS. Individuals with missing information (n=48) and those who reported being unemployed, retired or looking after the home (n=41) were excluded from the analysis. The sample mean age was 38.4 years (range 18–61), and more than two-thirds (68.6%) were female. Over half (51.7%) had university education. There were significantly more women among the excluded individuals, who were also older and had lower attained education level (P<0.01 for all variables). There was no significant difference between those included and those excluded in terms of number of symptoms (P=0.20) and level of fatigue (P=0.85). Scores on the cognitive and behavioural subscales were normally distributed.

Seventy-one (42.3%) of the patients reported long-term sickness absence. Both working patients and those on long-term sickness absence had high levels of symptom severity (Table 1 shows key results; for complete results see online Table DS1).
However, only physical fatigue and sleep were significantly worse among the patients with long-term sickness absence (β = 0.098, P < 0.05 and β = 0.075, P < 0.05 respectively). For cognitive and behavioural responses, patients reporting long-term sickness absence had significantly higher mean scores on the subscales embarrassment avoidance (β = 0.086, P < 0.05) and avoidance resting behaviour (β = 0.078, P < 0.05), and borderline significant higher levels of fear avoidance (β = 0.078, P = 0.05). The subanalysis using backwards stepwise regression produced a final model containing four elements; fear avoidance (P = 0.03), embarrassment avoidance (P = 0.05), physical fatigue (P = 0.09) and age (P = 0.001).

Discussion

Long-term sickness absence among patients with CFS was associated with physical fatigue, poor sleep, and cognitive and behavioural responses characterised by embarrassment over symptoms and avoidance behaviour.

The strengths of this study include its clinical setting, diagnostic procedures and the large amount of detailed information collected about each patient. The small sample size, multiple comparisons and the use of stepwise regression raises the risk of findings occurring by chance (type 1 error). In order to reduce this risk we carried out the minimum number of statistical tests required to examine our a priori hypotheses. As we were only able to look at cross-sectional associations, we cannot comment on cause and effect. The use of data from a specialised CFS clinic and the use of a new scale may limit the generalisability of our results.

To our knowledge, this is the first study to examine the associations between specific cognitive and behavioural responses and long-term sickness absence in patients with CFS. Our findings are in accordance with previous studies suggesting that factors other than symptom severity are important in predicting prognosis in CFS. Similar findings have occurred when the role of cognitive and emotional factors have been considered in musculoskeletal and cardiovascular disorders,12–14 with passive–reactive coping strategies, such as avoidance, appearing to be of particular importance in predicting occupational outcomes.15 We suggest that cognitive and behavioural responses have a role in predicting functional outcomes of any chronic illness, although the contested nature of CFS may increase their importance. This may accentuate any embarrassment over symptoms or fears that symptoms may get out of control. Such reactions, when combined with a tendency towards avoidant responses may contribute to an increasing spiral of avoidance of all social situations including work.

To date there is little evidence on the effectiveness of interventions to prevent long-term sickness absence and facilitate return to work in patients with CFS. The results of this study suggest that identifying and addressing avoidance behaviours and cognitions regarding embarrassment in interventions for CFS may enhance the chances of individuals returning to work.
Appendix DS1

Description of the cognitive and behavioural subscales assessed by the Cognitive and Behavioural Responses Questionnaire (CBRQ)

- **Fear avoidance**: avoidance of activities due to fear of worsening symptoms (e.g., I am afraid that I will make my symptoms worse if I exercise)
- **Catastrophising**: catastrophic cognitions regarding chronicity of symptoms (e.g., I will never feel right again)
- **Damage beliefs**: beliefs that symptoms and symptom severity reflect true damage to the body (e.g., the severity of my symptoms must mean there is something serious going on in my body)
- **Embarrassment avoidance**: avoidance of social situations due to feelings of shame and embarrassment over symptoms (e.g., the embarrassing nature of my symptoms prevents me from doing things)
- **Symptom focusing**: cognitive preoccupations on symptoms (e.g., when I am experiencing symptoms it is difficult for me to think of anything else)
- **All-or-nothing behaviour**: behaviour characterized by periods of high activity resulting in overextension and subsequent prolonged periods of resting (e.g., I tend to do a lot on a good day and rest on a bad day)
- **Avoidance resting behaviour**: excessive resting and avoidance of activity (e.g., I stay in bed to control my symptoms)

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Table DS1  Mean score (standard deviation) for symptom severity and cognitive and behavioural responses to symptoms among workers (n=97) v. individuals on long-term sick leave (n=71)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total with valid responses on scale, n</th>
<th>Workers, mean (s.d.)</th>
<th>Long-term sick leave, mean (s.d.)</th>
<th>Statistical significance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Symptom severity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of symptoms</td>
<td>166</td>
<td>5.93 (1.96)</td>
<td>6.37 (2.27)</td>
<td>β=0.037, P=0.318</td>
</tr>
<tr>
<td>CISR symptom scorec</td>
<td>119</td>
<td>12.99 (7.62)</td>
<td>13.04 (9.94)</td>
<td>β=0.007, P=0.865</td>
</tr>
<tr>
<td>Chalder Fatigue Scale Total</td>
<td>161</td>
<td>8.37 (2.86)</td>
<td>9.03 (2.56)</td>
<td>β=0.077, P=0.052</td>
</tr>
<tr>
<td>Chalder Fatigue Scale Physical</td>
<td>161</td>
<td>5.80 (1.87)</td>
<td>6.32 (1.64)</td>
<td>β=0.098, P=0.014</td>
</tr>
<tr>
<td>Chalder Fatigue Scale Mental</td>
<td>161</td>
<td>2.57 (1.33)</td>
<td>2.71 (1.20)</td>
<td>β=0.030, P=0.442</td>
</tr>
<tr>
<td>Jenkins Sleep Scale</td>
<td>163</td>
<td>10.65 (4.93)</td>
<td>12.38 (4.81)</td>
<td>β=0.075, P=0.048</td>
</tr>
<tr>
<td><strong>Cognitive and behavioural responses</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear avoidance</td>
<td>159</td>
<td>13.46 (4.02)</td>
<td>14.68 (3.42)</td>
<td>β=0.078, P=0.051</td>
</tr>
<tr>
<td>Catastrophising</td>
<td>164</td>
<td>7.48 (3.66)</td>
<td>8.03 (3.48)</td>
<td>β=0.023, P=0.547</td>
</tr>
<tr>
<td>Damage beliefs</td>
<td>162</td>
<td>10.42 (3.75)</td>
<td>11.38 (3.68)</td>
<td>β=0.048, P=0.207</td>
</tr>
<tr>
<td>Embarrassment avoidance</td>
<td>162</td>
<td>11.12 (5.38)</td>
<td>12.94 (5.07)</td>
<td>β=0.086, P=0.023</td>
</tr>
<tr>
<td>Symptom focusing</td>
<td>163</td>
<td>13.05 (5.30)</td>
<td>13.06 (5.06)</td>
<td>β=0.007, P=0.858</td>
</tr>
<tr>
<td>All-or-nothing behaviour</td>
<td>164</td>
<td>8.67 (4.74)</td>
<td>10.28 (5.05)</td>
<td>β=0.048, P=0.209</td>
</tr>
<tr>
<td>Avoidance resting behaviour</td>
<td>161</td>
<td>12.23 (4.63)</td>
<td>14.32 (5.90)</td>
<td>β=0.078, P=0.045</td>
</tr>
</tbody>
</table>

CISR, Revised Clinical Interview Schedule.

a. Individuals with missing responses on scale items excluded from the analysis.

b. Standardised coefficients from linear regression adjusted for age, gender and education.

c. Total score CISR symptoms without fatigue.
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