

*Citation for published version:*

Daniels, J, Brigden, A & Kacorova, A 2017, 'Anxiety and depression in chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): Examining the incidence of health anxiety in CFS/ME', *Psychology and Psychotherapy Theory, Research and Practice*, vol. 90, no. 3, pp. 502-509. <https://doi.org/10.1111/papt.12118>

*DOI:*

[10.1111/papt.12118](https://doi.org/10.1111/papt.12118)

*Publication date:*

2017

*Document Version*

Peer reviewed version

[Link to publication](#)

This is the peer reviewed version of the following article: Daniels, J. Brigden, A. Karcorova, A. (2017) Anxiety and depression in chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): Examining the incidence of health anxiety in CFS/ME. *Psychology and Psychotherapy*, 90(3)502-509, which has been published in final form at [10.1111/papt.12118](https://doi.org/10.1111/papt.12118) . This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving.

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Anxiety and depression in CFS/ME: examining the incidence of health anxiety in Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ME)

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## **Abstract**

*Objectives:* There is a lack of research examining the incidence of health anxiety in Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ME), even though this is an important research area with potentially significant clinical implications. This preliminary study aims to determine the incidence of anxiety and depression, more specifically health anxiety, in a sample of CFS/ME patients over a three month period.

*Design:* The research was a cross-sectional questionnaire-based study, using a consecutive sample of patients who were assessed in a CFS/ME service.

*Method:* Data was taken from the Short Health Anxiety Inventory and the Hospital Anxiety and Depression Scale to identify incidence of anxiety, depression and health anxiety.

*Results:* Data was collected from 45 CFS/ME patients over the sampling period. Thirty-one patients (68.9%) scored above the normal range but within the sub-clinical range of health anxiety and 19 patients (42.2%) scored within the clinically significant health anxiety range. Anxiety and depression were common, with prevalence rates of 42.2% and 33.3% respectively, which is comparable to data found in a recent large scale trial.

*Conclusions:* Health anxiety in CFS/ME patients is likely to be common and warrants further investigation to provide a better insight into how this may influence treatment and symptom management.

*Key words:* Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME); health anxiety; anxiety; depression.

## Practitioner Points

- Anxiety and depression were common in a sample of CFS/ME patients, with a high proportion meeting criteria for severe health anxiety.
- While CFS/ME and health anxiety are distinct and separate conditions, it is unsurprising that patients with CFS/ME, who commonly report feeling 'delegitimised', may experience high levels of anxiety relating to their physical symptoms
- Clinicians should consider screening for health anxiety due to the possible clinical implications for treatment; mutual maintenance may negatively influence treatment success in a complex condition such as CFS/ME
- Health anxiety has been found to be common across other chronic medical conditions but has been shown to be effectively treated with appropriately tailored interventions.

## **Introduction**

Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) is a debilitating condition characterised by excessive fatigue, joint pain and sleep disturbance. With prevalence rates of CFS/ME estimated at 0.17- 2.07% (Johnston et al., 2013), developing an efficacious and cost-effective treatment is a priority. However, the aetiology of CFS/ME remains poorly understood and treatment falls short of optimal outcomes: a recent meta-analysis (Castell, Kazantzis & Moss-Morris, 2011) indicated that gold standard treatment Cognitive Behaviour Therapy (CBT) (NICE, 2007) demonstrates only moderate improvements ( $g=0.33$ ). A recent study reported that 32% of the CFS/ME sample experienced co-morbid anxiety disorders (White et al., 2011). Due to the complex and heterogenous nature of this condition, it would be unsurprising if patients with CFS/ME experience high levels of health focussed anxiety.

High levels of health anxiety have been found to be common across a diverse range of medical conditions including cardiac, neurological and respiratory conditions (Tyrer et al., 2011), however no data exists on the incidence of health focussed anxiety in CFS/ME.

Individuals with CFS/ME commonly report symptom hypervigilance and beliefs that CFS/ME is serious and physiological in origin (Moss-Morris, 2005; Moss-Morris & Petrie, 2000), factors also found to maintain health anxiety (Salkovskis, 1996).

The aim of this preliminary study is to determine incidence of anxiety, depression, and specifically health anxiety in CFS/ME. Data will expand our understanding of this population and develop treatments to address outstanding clinical needs.

## **Method**

### Participants and recruitment

Recruitment spanned a 3-month period. Adults with a diagnosis of CFS/ME were recruited from a CFS/ME service offering evidence based multidisciplinary assessment and treatment as per NICE guidance (2007) (including psychology, physiotherapy and occupational therapy). Clinicians diagnosed patients according to the Fukuda criteria (Fukuda et al., 1994) during an assessment interview. A battery of standardised questionnaires assisted in diagnosis (table 1).

### Measures

This study used two of the questionnaires included in the battery: the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1990), and the Short Health Anxiety Inventory (SHAI; Salkovskis et al., 2002). Both measures consisted of 14 items using a 4 point likert scale (scoring 0-3) where higher scores indicate higher levels of health anxiety, and anxiety/depression. The HADS is separated into two 7-item subscales of anxiety and depression”

Both measures demonstrated reliability across numerous patient groups (Brennan et al., 2010; Alberts et al., 2013, respectively). A cut-off of 11 on the HADS was used to identify ‘definite’ cases of depression/anxiety (Brennan et al., 2010). A cut-off of 15 on the SHAI indicates above the normal range, but sub-clinical health anxiety (3 s.d. above the norm), 18 indicates significant levels of health anxiety (Rode et al., 2006).

We retained data relating to scores between 15-18 (sub-clinical health anxiety) as this is the first paper to explore incidence of health anxiety in CFS/ME and we believe it is of clinical interest to describe and report the group showing rates of health anxiety that are elevated from the norm.

*[Insert Table 1]*

### Statistical analyses

Data were normally distributed therefore a Pearson's product moment correlation was used to assess association and convergent validity. An independent t-test was used to test differences between dichotomous variables.

## Results

Eighty-seven patients attended the service during the sampling period. Of these, 77 were diagnosed with CFS/ME (89%), 49 consented to the study and 45 provided full data (58% of overall sample).

*[Insert Table 2]*

In this study the HADS anxiety and depression subscales and SHAI demonstrated good internal consistency (Cronbach's  $\alpha = .80, .84, .89$ , respectively).

HADS data indicated that 42.2% of participants scored over the cut-off for 'definite' anxiety, 33.3% scored above the cut-off for 'definite' depression. On the SHAI, 68.9% scored within the range of sub-clinical health anxiety, 42.2% scored in the significant health anxiety range. See table 2 for further descriptive statistics.

Correlational analysis between the SHAI and HADS-A indicated a moderate strength association, confirming expected levels of convergent validity ( $r(45) = .353, p = .017$ ).



Frequencies of definite cases on SHAI and HADS was used to devise a contingency table, indicating that sensitivity of the HADS-A ('definite case') to predict clinically significant health anxiety on the SHAI is 58%, specificity calculations indicate 69% of patients who did not reach definite case on the HADS would also not reach clinically significant health anxiety on the SHAI (table 3).

This is consistent with correlational analysis and clinical expectations: a proportion of patients with 'severe general anxiety' also have specific anxiety associated with their health others; have case levels of general anxiety without health related features.

*[Insert Table 3]*

There were no significant differences between the SHAI scores for males ( $M = 17.43$   $SD = 7.12$ ) and females ( $M = 18.06$   $SD = 7.63$ );  $t(43) = -.26$ ,  $p = .73$ ), nor age ( $r = -.25$ ,  $n = 45$ ,  $p = .10$ ).

## **Discussion**

The aim of this preliminary study was to establish incidence of anxiety, depression, and specifically health anxiety in CFS/ME. We believed that this information would contribute to an understanding of how targeted treatments can be developed to address the clinical needs of this population.

Findings are consistent with existing literature reporting high incidence of anxiety and depression in patients with CFS/ME (White et al., 2011). This study found a high incidence of health anxiety (42.2%) in comparison to the 24.7% reported in other medical settings (Tyrer et al., 2011). With uncertain prognosis, heterogeneous manifestation, as well as health professionals viewing the condition as contentious and lacking confidence and knowledge (Bayliss et al., 2016), it is understandable that CFS/ME may cause patients to worry about their health.

Participants completed questionnaires prior to their initial appointment, therefore the high incidence in this study may reflect elevated anxiety associated with the assessment process this should be explored further.

The mean SHAI score for the present sample (17.9) was higher than norms established for other health groups such as gastroenterology patients (11.4), General Practice patients (11.2) and anxiety sufferers (14.9) (Salkovskis et al., 2002). This finding contributes to the knowledge base relating to health anxiety across health conditions, but is of particular clinical interest given the complex nature of CFS/ME and the suggested interplay between health anxiety and CFS/ME in clinical practice (Daniels & Loades, 2016).

The small sample, modest response rate and disproportion number of females and Caucasian participants limited the generalizability of the results. A larger-scale study with a more representative sample could be used to replicate findings and establish more definitive normative

data for the SHAI in CFS/ME Future studies should give consideration to other key variables such as illness duration which were not explored within this preliminary paper.

Anecdotal feedback from the service lead indicated that a number of patients declined to participate due to the perceived implication that anxiety was the primary complaint rather than chronic fatigue: “one patient said crossly ‘I’m not a hypochondriac” (personal communication, Gladwell, 2014). This is consistent with high illness convictions commonly found amongst patients with CFS/ME (Moss-Morris, 2005; Moss-Morris & Petrie, 2000); patients may have interpreted the questionnaire as a rejection of an underlying physiological explanation for CFS/ME. Further research should explore the acceptability of this measure in the CFS/ME population and its suitability in capturing relevant data.

Results indicate that there may be high incidence of health anxiety in CFS/ME, which has been previously unreported. It is likely that severe health anxiety would impede treatment of CFS/ME if neglected as a clinical issue due to the complex and mutually maintaining nature of these conditions which share similar theoretical underpinnings and clinical features (Daniels & Loades, 2016). A recent large scale treatment trial CHAMP (Cognitive behaviour therapy for Health Anxiety in Medical Patients, Tyrer et al., 2014) yielded positive and cost-neutral outcomes in patients who experienced comorbid health anxiety and medical problems. Based on current findings, future research should build on Daniels & Loades (2016) work to establish whether adapted CBT for health anxiety in medical problems could optimise outcomes for the CFS/ME subgroup who experience significant levels of health focussed anxiety.

**Financial Support**

This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

**Conflict of Interest**

None.

### **Suggestions for further reading**

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Table 1.

*Fukuda Diagnostic Criteria and Questionnaire Measures*

<b>Major Criterion</b>	<b>Symptoms</b>	<b>Signs</b>	<b>Questionnaire measures</b>
Major criterion: New onset of fatigue causing 50% reduction in activity for at least 6 months	<ul style="list-style-type: none"> <li>• Mild Fever</li> <li>• Recurrent sore throat</li> <li>• Painful lymph nodes</li> <li>• Muscle weakness</li> <li>• Muscle pain</li> <li>• Prolonged fatigue after exercise</li> <li>• Recurrent headache</li> <li>• Migratory joint pain</li> <li>• Neurological or psychological complains, including sensitivity to bright lights forgetfulness, confusion, inability to concentrate, excessive irritability, and depression</li> </ul>	<ul style="list-style-type: none"> <li>• Low-grade fever</li> <li>• Non exudative pharyngitis</li> <li>• Palpable or tender lymph nodes</li> </ul>	<ul style="list-style-type: none"> <li>• Chalder Fatigue Scale</li> <li>• SF-36</li> <li>• EQ-5D</li> <li>• Hospital Anxiety and Depression Scale</li> <li>• Health Anxiety Inventory</li> <li>• Self-efficacy scale</li> <li>• Visual Analogue Scale</li> </ul>
Minor criterion: Presence of 8 of the 11 symptoms and 2 of the 3 signs	<ul style="list-style-type: none"> <li>• Sleep disturbance (hypersomnia or insomnia)</li> <li>• Sudden onset of symptom complex</li> </ul>		

Table 2.

*Demographic information and clinical findings*

	CFS/ME participants (n= 45)
Gender	14 Male: 31 Female
Mean age (SD)	38.7 years (13.1)
Ethnicity	43 White: 2 Asian
Mean HADS-A score (SD)	10.0 (4.7)
Mean HADS-D score (SD)	8.9 (3.8)
Number (%) of participants with HADS-A score $\geq$ 11	19 (42.2)
Number (%) of participants with HADS-D score $\geq$ 11	15 (33.3)
Mean SHAI score (SD)	17.9 (7.4)
Number (%) of participants with SHAI score $\geq$ 15	31 (68.9)
Number (%) of participants with SHAI score $\geq$ 18	19 (42.2)

Table 3.

*Contingency table of HADS-A and SHAI “definite” cases*

		HADS- A		Total
		Not Case ( $<11$ )	Definite Case ( $\geq 11$ )	
SHAI	Not clinically significant ( $<18$ )	18	8	26
	Clinically significant ( $\geq 18$ )	8	11	19
Total		26	19	45