



# Enhanced psychological flexibility and improved quality of life in chronic fatigue syndrome/myalgic encephalomyelitis



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## ABSTRACT

**Objective:** Psychological Flexibility (PF) is a relatively new concept in physical health. It can be defined as an overarching process of being able to accept the presence of wanted/unwanted experiences, choosing whether to change or persist in behaviour in response to those experiences. Associations between processes of PF and quality of life (QoL) have been found in long-term health conditions such as chronic pain, PF has not yet been applied to Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME).

**Methods:** Changes in PF, fatigue severity and QoL were examined in one hundred and sixty-five patients with CFS/ME engaged in a six-week outpatient interdisciplinary group treatment programme. Participants were assessed using a series of self-report measures at the start of the start (T1) and end of a six-week programme (T2) and at six months follow up (T3).

**Results:** Significant changes in PF and QoL were observed from pre-treatment (T1) to post treatment follow-up (T2 and T3); changes in fatigue severity were observed from T1 to T3 only. Controlling for fatigue severity, changes in the PF dimension of activity/occupational engagement were associated with improvement in QoL at six month follow up (T3) but not at six weeks post programme (T2).

**Conclusion:** Findings indicate an interdisciplinary group treatment approach for people with CFS/ME may be associated with improved QoL, processes of PF and fatigue severity, supporting a link between PF and long term health conditions. Results highlight links between PF and patient QoL in CFS/ME and the value of interdisciplinary treatment approaches in this patient population.

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## 1. Introduction

Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) is a debilitating illness, characterised by persistent extreme fatigue, unrelated to exertion and not relieved by rest. Other common symptoms are muscle cramps, sleep disturbances and cognitive difficulties [1]. Patients have described experiences of social isolation, emotional turmoil and inability to engage in usual activities due to physical and mental exhaustion [2]. The precise medical pathophysiology of CFS/ME is unknown [3]. Despite accumulating evidence recognising it as affecting 250,000 people in the UK [4], controversy surrounding this diagnosis is reflected in CFS/ME patient experiences of feeling stigmatised and marginalised [5]. Two main diagnostic criteria commonly used to diagnose CFS/ME [6] are those of the CDC (Centers for Disease Control and Prevention, US) [1] and Oxford [7], with the former most commonly used in the UK [8].

Patient experience of the uncertainty of CFS/ME is often reflected in attempts to gain control over and prevent the onset of fatigue [9].

Behaviours to gain control may not always be beneficial to wellbeing if they are not aligned with the long-term values and goals of the patient. When the desire to control fatigue becomes overwhelming, behaviour can become rigid and inflexible, impeding upon patients' ability to achieve a balance between accepting the implications of CFS/ME and living their lives [9].

### 1.1. Psychological flexibility (PF)

The management of CFS/ME has been linked to processes associated with the concept of Psychological Flexibility (PF) [10]. PF is defined as an overarching process of being able to accept the presence of both unwanted and wanted experiences, using this awareness to choose whether to change or persist in behaviour in response to those experiences, depending on what is most adaptive and functional for a meaningful life [11]. Mindfulness, the act of purposefully connecting with present moment experiences, fully and without judgement, is thought to enable PF processes [12,13]. It can be considered a platform for the development of PF, in which self-awareness and exploration from paying attention is related to cognitive defusion and acceptance, to influence purposeful behavioural choices [14,15].

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Attempts to gain complete control over physical sensations can present a paradox: avoiding experiences that have become associated with fatigue can lead to a narrowing of the patient's behavioural repertoire and reduce value based living, resulting in less meaningful adaptive behaviours. Through intervention approaches patients learn over time to manage their energy through effectual behaviour change, reducing fatigue severity [16,17]. The most recent behaviour change model of PF [18] constitutes six related aspects: i) 'Cognitive defusion' (a process through which experiences become less dominated by thoughts, language and verbalised rules); ii) 'Acceptance' (making room for unwanted experiences and creating space to engage with bodily sensations); iii) 'Contact with the present moment' (ability to fully engage with current experiences without focus on past or future events); iv) 'Self as context' (experiences of the present moment are defined by 'pure awareness', or the 'observing self'); v) 'Values' (desires that can be reflected in our behaviour and relate to goals); vi) 'Committed action' (carrying out effective behaviours that are in line with and guided by our values) [12,13,19]. Mindfulness is a wellbeing strategy used alone or as part of other psychological interventions [20,21] and links to the first four of these six PF core processes [22]. Quality of life is an important outcome to assess since it can indicate overall level of wellbeing in different life domains, which may reflect experience of value based living and acceptance.

Whilst PF processes have largely been investigated in the context of chronic pain [23–27], no studies have explicitly used PF as a framework to understand processes in CFS/ME. There are comparable features between these two populations, including the occurrence of pain and fatigue, sleep disturbances, limitations in physical activity, muscle weakness and digestive problems [28]. There are also likely to be differences between the experience of chronic pain and CFS/ME [9,29]. The length of time it takes CFS/ME patients to develop processes of PF and to experience the benefits of PF on their QoL may be influenced by the fluctuating nature of the condition.

The present study examined processes of PF within an adult CFS/ME population. It aimed to increase understanding of PF in this population by investigating changes in PF processes, fatigue severity, and QoL in CFS/ME over six months, assessed before and after treatment. The treatment programme was for clinical purposes to improve condition management and quality of life and not specifically designed with the aim of improving PF. It was hypothesised that there would be changes in fatigue severity, PF and QoL following the six week treatment programme and at six month follow-up (pre to post treatment assessments T1 to T2/T3). Secondly, it was hypothesised that changes in PF would be associated with changes in patient QoL outcomes at six month follow-up when controlling for changes in fatigue severity across respective time points.

## 2. Method

### 2.1. Participants

Participants were 165 patients who attended a treatment programme at a tertiary care Adult Fatigue Management Service in South West England between 2006 and 2014. Women formed the larger proportion of participants (78.2%), as is typically the case for CFS/ME [30]. Eligibility criteria required participants to be over 18 years of age and have been diagnosed with CFS/ME (CDC criteria) or Post Viral Fatigue Syndrome (PVFS). PVFS was recorded for patients who at study entry, diagnosis was either unknown or for who symptom duration had been less than four months (Fukuda criteria for CFS [1]). Combined inclusion was justified on the basis that patients with CFS and PVFS were treated alike in the programme and both syndromes have comparable key diagnostic indicators. In this sample, the prevalence of PVFS was approximately 3–5% of participants. All patients were between the ages of 18 and 70 years ( $M = 40.54$ ,  $SD = 12.075$ ), the majority were White British (95.8%), over half were married/living with a partner (57.1%) and almost a third were single (29.2%). Mean duration

since CFS/ME symptom onset was 56.15 months (mode: 8 months; range: 3–408 months).

The treatment programme adopted the recommendations of the UK NICE guidelines 2007 [4] for the treatment and management of CFS/ME. It employed the evidence base of cognitive behavioural therapy (CBT principles), an activity management approach (comparable to Graded Exercise Therapy), goal setting, relaxation techniques, communication skills and third wave CBT approaches, such as mindfulness, alongside pharmacological treatment delivered by the patient's GP if appropriate. Aspects of the treatment programme incorporated the facilitation of developing PF. The ethos of the programme was centred on the principles of occupational science [31,32], enabling an interdisciplinary and holistic approach to treatment with an emphasis on the importance of action/doing for the individual. The interdisciplinary team comprised Occupational Therapists, Physiotherapists, and Practitioner Psychologists. Following individual tailored assessment the group treatment sessions were 2 h long, once a week, for 6 weeks, with one follow up group session held 6 months after the last session. Average group size comprised of eight patients.

Using data collected at initial assessment (pre-treatment/T1), at the end of the six week programme (post treatment/T2) and six months after the programme finished (six month follow up/T3) provided an investigation of PF over time, situating the research within the current evidence base for CFS/ME in adults [4].

### 2.2. Measures and procedure

Participants completed a self-report questionnaire pack at all assessment points collected as part of routine practice and provided informed consent for their data to be used for research purposes. Ethical approval for the study was received from the relevant local institutional ethics committee and ethical procedures were followed throughout. This CFS database has retrospective and prospective national ethical approval (NHS ref 09/H0101/58). Questionnaire packs included the following assessments:

### 2.3. Psychological flexibility

In accordance with previous research, PF was measured using items in the Chronic Pain Values Inventory (CPVI) [33], that assessed 'success in value based living'. The CPVI wording was adapted to reflect the presence of fatigue as opposed to pain (recommended in the CPVI appendix). PF was also measured using a previously adapted version of the Chronic Pain Acceptance Questionnaire (CPAQ) [33], the Fatigue Acceptance Questionnaire (FAQ) that replaces the word 'pain' with 'fatigue' [34]. The FAQ is made up of two subscales: 'activity engagement' reflects the pursuit of meaningful activities in the presence of fatigue; and 'fatigue willingness' reflects a relative absence of attempts to avoid or control fatigue. Separate scores from the two subscales were used to measure PF for the analyses in the present study. Cronbach's alpha scores in the present study were 0.88, 0.90 and 0.91 respectively for activity engagement from pre to follow up assessment and 0.43, 0.63 and 0.73 respectively for fatigue willingness from pre to follow up assessment. The concept of PF is difficult to measure [11]. It is frequently seen as a single construct and focus on components of the model can make it difficult to investigate the full meaning of the construct yet considering specific PF components enables a more detailed examination and may lead to development of more targeted interventions. It is acknowledged that there are other processes incorporated in the PF construct that are not being assessed in the current study.

### 2.4. Quality of life

Perceived QoL was assessed using the Sickness Impact Profile (SIP) [35], a well established behaviourally based measure. It reflects perceived QoL in 12 areas of activity including home management, social

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