

# 'It's personal to me': A qualitative study of depression in young people with CFS/ME

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## Abstract

**Background:** Paediatric chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) has a prevalence of 0.4–2.4% and is defined as 'generalised disabling fatigue persisting after routine tests and investigations have failed to identify an obvious underlying cause'. One-third of young people with CFS/ME have probable depression. Little is known about why depression develops, the relationship between depression and CFS/ME, or what treatment might be helpful.

**Methods:** We conducted nine semi-structured interviews with young people with CFS/ME (aged 13–17 years, 8/9 female) and probable depression, covering perceived causes of depression, the relationship between CFS/ME and depression, and treatment strategies.

**Results:** Most thought CFS/ME caused depression. Many discussed a cyclical relationship: low mood made CFS/ME worse. A sense of loss was common. CFS/ME restricted activities participants valued and changed systemic structures, causing depression. There was no single helpful treatment approach. Individualised approaches using combinations of cognitive behavioural therapy (CBT), medication, activity management and other strategies were described.

**Conclusion:** This study suggests that depression may be secondary to CFS/ME in young people because of the impact of CFS/ME on quality of life. Clinicians treating young people with CFS/ME need to consider strategies to prevent development of depression, and research is needed into approaches that are effective in treating CFS/ME with co-morbid depression.

## Keywords

Chronic fatigue syndrome, CFS/ME, depression, young people, adolescents

## Introduction

The prevalence of paediatric chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) is between 0.4% and 2.4% (Chalder, Goodman, Wessely, Hotopf, & Meltzer, 2003; Crawley,

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2014; Crawley, Emond, & Sterne, 2011). CFS/ME is defined as ‘generalised fatigue persisting after routine tests and investigations have failed to identify an obvious underlying cause’ (Royal College of Paediatrics and Child Health (RCPCH), 2004). To be diagnosed with CFS/ME, young people must have experienced persistent or recurrent fatigue which has substantially limited their physical functioning for at least 3 months, with the presence of at least one additional symptom, including headache, joint and muscle pain, cognitive dysfunction, painful lymph nodes, sore throat, sleep disturbance, dizziness, nausea, flu-like symptoms or heart palpitations (National Institute for Health and Care Excellence (NICE), 2007; RCPCH, 2004). CFS/ME has a substantial negative impact on young people’s quality of life (Winger et al., 2015). On average, young people with CFS/ME are absent from school for 1 year, and around 50% of young people are bed bound at some point during their illness (Garralda & Rangel, 2004). Unidentified CFS/ME is a major cause of school absence, with one school surveillance study reporting that approximately 1/100 young people missed more than 1 day per week of school (Crawley et al., 2011).

The UK NICE recommends that young people with CFS/ME are offered either cognitive behavioural therapy (CBT), graded exercise therapy (GET) or activity management (AM) (NICE, 2007). CBT for CFS/ME includes behavioural components which focus on finding a baseline level of activity that is then gradually increased and on improving sleep patterns, and a cognitive component, which targets unhelpful thoughts, assumptions and beliefs about the patient’s illness and symptoms (Mackenzie & Wray, 2013). GET is a structured exercise programme focusing specifically on physical activity. AM provides the behavioural component of CBT without emphasising the cognitive component. There is good evidence that CBT delivered individually (Stulemeijer, de Jong, Fiselier, Hoogveld, & Bleijenberg, 2005), with biofeedback (Al-Hagggar, Al-Naggar, & Abdel-Salam, 2006) or via the Internet (Nijhof, Bleijenberg, Uiterwaal, Kimpen, & van de Putte, 2012), is effective at 6 months compared to waiting list or usual medical care. Despite this, at least 20% of young people who access specialist care do not recover at 6 months post-diagnosis (Chalder, Deary, Husain, & Walwyn, 2010; Gordon, Knapman, & Lubitz, 2010; Stulemeijer et al., 2005).

Mood disorders are common in paediatric CFS/ME (Bould, Collin, Lewis, Rimes, & Crawley, 2013; Carter et al., 1999; Garralda, Rangel, Levin, Roberts, & Ukoumunne, 1999; Smith, Martin-Herz, Womack, & Marsigan, 2003; Van Middendorp, Geenen, Kuis, Heijnen, & Sinnema, 2001). Almost 30% of young people with CFS/ME have probable clinical depression (Bould et al., 2013), which is characterised by low mood and/or loss of pleasure in most activities (NICE, 2015). Young people with CFS/ME who have co-morbid depression are more disabled, and experience greater pain and worse fatigue than those without depression (Bould et al., 2013). Experiencing depression in adolescence (in the absence of CFS/ME) has been shown to increase the risk of adult depression, interpersonal difficulties and suicide (Fombonne, Wostear, Cooper, Harrington, & Rutter, 2001). Interactions between CFS/ME and depressive disorders and primacy are yet to be established; for example, it is possible that depression is caused by CFS/ME, in direct relation to the severity of symptoms, or that depression affects the severity of CFS/ME. It is also not clear what impact co-morbid depression has on recovery in CFS/ME, or what the most effective treatment approach is for young people with both depression and CFS/ME.

This study aimed to explore the experiences of young people with CFS/ME and depression in order to understand their views on why low mood developed, the impact of having low mood and what they had found to be helpful and unhelpful in treatment.

## **Methods**

### ***Recruitment***

We recruited participants who had first been assessed (between 2013 and 2015) by the Royal National Hospital for Rheumatic Diseases (Bath, UK) paediatric CFS/ME service – a large regional, and national, National Health Service (NHS) specialist service. Young people were diagnosed with CFS/ME after a thorough assessment which included screening for other disorders associated with fatigue (NICE, 2007; RCPC, 2004). The specialist paediatric CFS/ME service is provided by a multidisciplinary team of doctors, occupational therapists, physiotherapists and psychologists. Eligible patients were given a recruitment pack containing a participant information sheet and were asked to return the ‘consent to contact’ form to the research team if they wanted to participate in the study. Once the ‘consent to contact’ form was received, a researcher telephoned the young person to provide more information and arrange a time to visit the young person to conduct the interview.

### ***Eligibility***

Young people were eligible if they were aged between 12 and 18 years, had a primary diagnosis of CFS/ME and had co-morbid low mood. Low mood was defined as a depression subscale score of >9 on the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) either at assessment or at subsequent treatment appointments with the specialist CFS/ME service. Young people were excluded from the study if they were housebound (unable to attend outpatient appointments).

### ***Patient-reported measures***

At assessment, patients complete questionnaires including the 36-Item Short-Form Health Survey (SF-36) physical function subscale (Ware & Sherbourne, 1992), the Chalder Fatigue scale (Chalder et al., 1993) and the HADS (Zigmond & Snaith, 1983). They also report their duration of illness and their typical school attendance (as a proportion of the expected number of days). The HADS is a 14-item questionnaire developed to measure symptoms of anxiety and depression in a general medical population. It asks respondents to rate, on a 4-point scale (0–3), the extent to which they have experienced each of seven depression symptoms and seven anxiety symptoms over the past week. Scores can be used to aid the identification of clinical levels of depression and anxiety symptomatology using published cutoff scores. The HADS has been validated for use with young people and subscale scores of >9 are generally assumed to indicate probable depression (White, Leach, Sims, Atkinson, & Cottrell, 1999). The HADS is used routinely in the specialist CFS/ME service to screen for depression and anxiety at assessment. It is also used if clinicians suspect the young person has become depressed.

### ***Sample***

Out of 35 potentially eligible participants identified by medical record review, nine participants were recruited, of whom eight (89%) were female (Table 1). Participants had been ill for a median of 12 months, and 78% (7/9) had <40% school attendance, i.e. 2 days or fewer per week. Participants were representative of the clinical cohort, except they had higher HADS depression scores (median

**Table 1.** Participant demographics and questionnaire scores.

Demographic or clinical variable	Participants (N=9)	Study population (N=849) <sup>a</sup>	p-value <sup>b</sup>
Female, n (%)	8 (88.9%)	609 (71.7%)	.46
Age (years), median (IQR)	14 (14–15)	14 (13–15)	.87
Duration of illness (months)	12 (8.5–37.5)	12 (8–24)	.88
School attendance <40%	7 (77.8%)	470 (58.1%)	.32
HADS-D score (range 0–21), median (IQR)	11.5 (10.5–12.5)	7 (5–10)	.003
HADS-A score (range 0–21), median (IQR)	12 (9.5–14)	8 (5–12)	.03
Disability (SF-36 physical function, range 0–100)	45 (30–50)	50 (30–70)	.45
Fatigue (Chalder fatigue scale, range 0–33)	29 (25–31)	25 (22–29)	.05

IQR: interquartile range; HADS: Hospital Anxiety and Depression Scale; SF-36: 36-Item Short-Form Health Survey.

<sup>a</sup>Characteristics are shown for all paediatric patients aged 12–18 years treated by the specialist service between 2008 and 2015.

<sup>b</sup>Fisher's exact test for sex and school attendance, Kruskal–Wallis test for all other variables (alpha level of .05).

11.5 vs 7, Kruskal–Wallis,  $p = .003$ ) and anxiety scores (median 12 vs 8, Kruskal–Wallis  $p = .03$ ), and slightly higher fatigue scores (median 29 vs 25, Kruskal–Wallis  $p = .05$ ).

## Interviews

A semi-structured topic guide was developed for the interviews, focusing on the young person's responses to the depression items on the HADS questionnaire, why young people felt they had become low in mood, factors contributing to low mood, whether their CFS/ME preceded or followed their low mood, what treatment strategies were helpful and unhelpful and whether anything else would have helped (see Appendix 1). Participants completed a 'consent to interview' form before the interview. The topic guide was used flexibly, and the interviewer used open questions while following its structure. Interviews were digitally recorded with participants' consent, transcribed verbatim and anonymised.

## Data analysis

Data were collected between November 2013 and January 2015. Analysis was ongoing and iterative. Sample size was determined by data saturation, which we judged to be when no themes emerged from two interview transcripts. After initial familiarisation with the data and transcription of each interview, the researchers (A.K.T., M.L. and E.C.) each independently read through the first three transcripts and generated potential codes. Researchers then met together to discuss and compare codes, and began to combine the codes into themes. There was little difference in coding between researchers, but where this occurred, we discussed the coding further and E.C. led the final decision. This process continued iteratively through the remainder of the analysis. Transcripts were imported into NVivo (NVivo qualitative data analysis software, Version 10, 2012; QSR International Pty Ltd), where they were analysed thematically using techniques of constant comparison. Thematic analysis was used as a means of identifying, analysing and reporting patterns in the data (Braun & Clarke, 2006). It was selected due to its flexibility, which allows categories to emerge from the data. Demographic and patient-reported characteristics of the sample were compared with the cohort from which the sample was drawn using Fisher's exact test for categorical

**Table 2.** Summary of themes and subthemes that emerged from the data.

Main themes	Sub-theme	Sub-sub-themes
The relationship between mood and fatigue Mechanism of the CFS/ME-mood relationship	Causality	Fatigue predating low mood
	Restricted activity	'Vicious cycles'; a complex relationship whereby symptoms (and/or management plans) initially reduce or impair activity. A cyclical relationship then develops between restricted activity, mood and negative/anxious thoughts.
	A changing role within social environments and wider systems	Symptoms (and/or management plans) cause changes within friendship groups, families and education system. Negative perceptions, for example, loss and low mood develop a cyclical relationship.
Managing mood	Loss	Being a teenager, Education, Social life, Family, Self-identity, Spontaneity
	Individualised approach	CBT, activity management, medication, other helpful strategies

CFS/ME: chronic fatigue syndrome/myalgic encephalomyelitis; CBT: cognitive behavioural therapy.

variables and Kruskal–Wallis test for continuous variables. An alpha level of .05 was used for all statistical tests.

### *Ethical approval*

The study was granted ethical approval by West of Scotland REC 5 (REC reference: 13/WS/0265).

## **Results**

Semi-structured interviews were conducted with eight patients at home and one participant on the phone. Six young people were interviewed alone, and three with a parent present. From the analysis of the qualitative data, three overarching themes emerged: the relationship between mood and fatigue, mechanisms of this relationship and managing mood (Table 2). Illustrative quotes are provided, identifiable by participant number.

### **The relationship between mood and fatigue**

Participants described a complicated relationship between their mood and fatigue. The majority of participants believed their CFS/ME to have been caused by a physical event, such as glandular fever, an operation to remove a kidney or appendix, kidney stones, tonsillitis or Hashimoto's. The majority of participants (6 of the 9) felt that CFS/ME predated their low mood:

It's normally fatigue for a while, get symptoms, and then having to limit myself and what I can do, and then that results in low mood cos I can't do what I want to do. (YP1)

I suppose it's the fatigue symptoms that come, sort of come up first . . . and then I sort of get the low mood with it or sort of after it. (YP3)

However, this was not always true; one felt that their CFS/ME and low mood occurred together, and two experienced 'stress' or depression prior to developing CFS/ME:

Um, I think low, I felt very very low at the beginning, but I think I started to feel low and then got very tired. (YP2)

## **Mechanisms for the relationship between CFS/ME and low mood**

Participants talked about possible mechanisms for the link between CFS/ME and low mood, principally restricted activity and a changing role within social environments and wider systems.

### *Restricted activity*

Participants commonly talked about the relationship between CFS/ME symptoms, the management of symptoms and changes in activity and mood. Some participants presented a linear causal relationship between the symptoms of CFS/ME (fatigue, pain, cognitive impairment), which prevented, restricted or interfered with activities. This in turn impacted on their mood. Not being able to do activities they enjoyed or engage in them fully provoked negative emotions such as low mood, frustration, boredom and hopelessness. They also described a reduction in positive thoughts and emotions such as excitement and being able to look forward to things:

I think not doing the stuff I used to puts me in a bad mood. (YP8)

You're stuck at home, so everything you'd enjoy, going out then coming home and being able to sit with your family but obviously if you're sat at home all day then all night and then all day the next day you just get bored of the same four walls. (YP4)

Having to limit myself and what I can do and then that results in low mood because I can't do what I want to. (YP1)

In other cases, participants described a more complex relationship involving 'vicious cycles'. Symptoms of CFS/ME directly limited activity; however, negative thoughts and feelings about the symptoms were also implicated in activity restrictions and inability to gain pleasure from activity. In turn, activity restriction contributed to low mood and negative cognitions. One participant described how their symptoms of fatigue and sickness directly restricted activity. In addition, the experience of the condition was associated with anticipation of negative consequences and stress, contributing to avoidance of activity:

Sometimes I arrange to meet up with friends and I can't even . . . turn up because I'm that stressed about going and being sick or having diarrhoea and that, and I just get so worked up about it, and like, even going on public transport I get quite worried. (YP6)

In another example, the negative appraisals that the participants made, related to restriction imposed by the condition, meant that they were unable to take pleasure from activities in which they did partake:

If I went out with my friends . . . I think well I was happy about seeing them but then I'd think about the downside of it like if I wasn't going to see them for a long time afterwards and then I start thinking about the downside rather than that I'd seen them and that's the good side. (YP2)

Constantly thinking about how, um, how much time you've got left and whether you should be doing this activity or not. So, um . . . just inevitably less enjoyable. (YP1)

The role of appraisal (i.e. interpretation) in mediating the relationship between activity restriction and low mood is further illustrated by the experience of one participant who talked about their improvement in mood. Although still experiencing activity restrictions, this participant was engaging in active management strategies and held more positive beliefs, such as a sense of self-efficacy:

I've got my limit and as long as I stay within the limit, I can have friends round for a couple of hours, I can do that, like I can do that safely without feeling awful the next day, so that's why I look forward to things a little bit more because then I know I can do them and still be OK. So . . . I know my limits and I know when I need to get rest so I can control it a little bit more. (YP5)

### *A changing role within social environments and wider systems*

All participants talked about the challenges of negotiating their social environments and wider systems (friendship groups, families and the education system) due to CFS/ME. Young people described unhelpful behaviours, negative cognitions and difficult emotions related to these challenges.

*Friends.* The majority of young people talked about negative experiences with their peers as a result of having CFS. Participants highlighted a general inability to sustain social relationships. They talked about difficult responses from their friends; participants commonly talked about a lack of understanding, negative attitudes and described a failure of their friends to accommodate and adapt to their condition. Some of the young people described how these negative responses were related to the specific nature of the condition – invisible, fluctuating, not widely known or recognised:

I was hardly ever at school really. And I got a lot of . . . you know, comments and things about it. (YP5)

I say that all the time. It's cos they don't know what it is so they . . . when I go out they see me and I'm fine. They don't see the bit after when I come in and when I've crashed and burned, and they don't see that. Obviously they don't understand the full . . . bit of it. (YP4)

The participants described the emotional impact of these social changes. They talked about fears of social judgment, perceptions of not fitting in and feelings of loneliness, frustration, anxiety, low mood and loss:

I always feel really low because my friends don't think it's a real thing. (YP1)

I think the low mood started in . . . when I got put off from school and when a lot of my friends pretty much dumped me. As you can imagine it's pretty lonely. (YP8)

But they make a joke and I'm like, 'well, you're actually really really wrong about that'. And it's kind of like . . . now I feel really really isolated because they're going on about it and I don't wanna upset them by correcting them, but . . . they're wrong! (YP5)

The participants described their responses to these challenges, describing strategies such as lack of communication, passive communication, withdrawal and avoidance:

And I can't do that. But I'll do it anyway cos I don't want to feel like a hassle. And then I come back and then I like . . . (YP4)

A number of participants indicated that building supportive peer groups, in particular developing connections with others who have CFS/ME, could be a helpful intervention:

Maybe like set up a group for children who've got it and they can talk to people who've got it, confide in them and that kind of thing. (YP6)

Developing interpersonal skills to help their peer groups understand and adapt to the condition was also highlighted:

If at the clinic they, sort of, went through a way to explain it to your friends, that might help you explain it. So that they understand better and it makes you feel a little bit less isolated. (YP1)

**Family.** Young people talked about the impact of CFS/ME on their family and changes in family dynamics, and how this made them feel low. Participants talked about their family suffering as a result of their condition, and also talked about increased dependence on their family:

It's affecting my family and friendships and that has been really one of the worst things for me, cos, um . . . cos it has, its affected things and also like seeing my mum and dad get upset about it and that is not very nice for me my dad owns a business and my mum's the manager and I think . . . their stress of work and being ill as well, it's quite stressful for them. It sometimes makes me feel low because I don't want them to stop doing what they're doing just for me. (YP3)

Yeah. I depend on my mum a lot. Cos obviously I can't walk around to meet friends and I can't be home alone. (YP4)

**Education system.** Almost all the participants described schools and colleges as inflexible, unhelpful, un-empathetic and invalidating. Again, participants related this to the specific nature of the condition – invisible, fluctuating, not widely known or recognised. Young people identified this as a cause of increased anxiety and low mood:

I was one of those rare species of child that actually enjoyed going to school . . . they had a student that enjoyed learning and they sort of took that away from me with the way they treated me. And I, it just kind of made me feel not worth it . . . they stopped paying attention to me and it kind of made me feel like a statistic or a problem that was going to affect their results table, and that was quite a horrible feeling really. (YP3)

**Loss.** A strong theme underpinning both the restriction in activity and the systemic changes was the theme of loss. The young people talked about the impact of their difficulties on the normative processes of being a teenager, and all the things associated with this: education, social life, family, self-identity and spontaneity:

You don't get to do the spontaneous things you're meant to do as a teenager . . . like you've been picked out by one of those grabbers out of a toy machine and you've literally been chucked down into the box and just left. (YP4)

## Managing mood

Young people found different approaches helpful. The importance of an individualised approach was emphasised:

I don't think that there is any other way really that you can sort of help them or support them . . . cos it is different for everyone, they're sort of, I think everyone just has to find their own way to deal with it, and



you know, deal with it within the family and that, and I think . . . no-one can sort of tell them how to do that because it's something that you've just gotta, like, find out for yourself really. (YP3)

**CBT.** Some participants talked about finding CBT helpful:

Originally I thought it was a bit of a waste of time but once I'd actually finished the sessions then I was able to reflect back and actually they were really beneficial. (YP1)

[re CBT] . . . You end up answering your own question, because you're talking about it and you realise and you make links with stuff. That's helped. (YP4)

Other participants were unsure about the utility of CBT:

I don't know if [CBT] helped me with the feeling low. (YP7)

The combination treatment of CBT and medication was also discussed:

[CBT] was a lot more helpful teamed with my medication than on its own. Once I was in a better frame of mind it really did help. But beforehand it was just . . . it wasn't helpful for me really because I was so down. Once I'd got on my medication I'd had a little bit of a boost, my mood was better and I was able to deal with it a bit better. (YP5)

One participant talked specifically about how they continue to use CBT in their lives, demonstrating a clear understanding of the cognitive behaviour therapy model and principles:

I don't think I like use it on a day to day basis, but, like, everyone has moments when they feel a bit down, so um . . . what I did was sort of . . . make a physical note of something, you write it down, for and against, is your feeling and thought rational, and then, that, that helps sort of grade whether I was just being silly or it was actually a worthwhile thought. (YP1)

**AM.** Young people recognised that AM could be a helpful approach, for example, by giving them things to look forward to. Achieving a balance of activities within one's limits was emphasised:

As long as I stay within the limit, I can have friends round for a couple of hours . . . so that's why I look forward to things a little bit more. (YP5)

. . . I'd probably say just to reinforce about getting the balance of your life right. And they did that with me but I probably didn't appreciate it as much as what they actually said. It's really important to have a balance. (YP1)

At times, participants also talked about having to think more about what activities they invested energy in, which in itself seemed to detract from the experience of the activity itself to some extent, thus undermining their sense of enjoyment and/or achievement in the activity:

It's quite upsetting really to sort of not be able to do something as simple, like, um, like doing my hair, cos other people, like, it used to be sort of something I just did, it wasn't . . . but now it's like something that I've really gotta think about, 'do I do this, or do I not?' which is quite difficult because it's not, like, you shouldn't have to, it's not natural to have to stop and think 'do I have the energy to do this or do I not?' kind of thing. So it's quite, it takes quite a bit of getting used to. (YP3)

**Medication.** Young people generally did not mind taking medication providing they found it helpful:

It doesn't really bother me I guess because it helps me. (YP4)

Definitely [found it helpful]. If I hadn't gone on medication at that point, I would have been very very very bad, you know. (YP5)

It's not nice having to take medication but if it helps then, you know. It's there to help you so you might as well take it. (YP5)

**Other helpful strategies.** Young people felt that better support from education systems could have helped:

Mainly, I think, making schools and colleges understand a bit better . . . once people are more aware of it, it'll be a lot easier to just cope with it. (YP5)

Participants also felt that building supportive networks could be beneficial; this includes developing relationships with other young people with CFS/ME. They talked about the potential being of feeling understood and less alone:

Talking to someone else with ME . . . might not make you feel so isolated. (YP1)

## Discussion

This is the first study that we are aware of which has asked young people with CFS/ME about depression, and which has reported the data as explained and experienced by young people. Young people said that both CFS/ME and depression significantly impacted on their quality of life. Most thought their CFS/ME occurred first and caused their depression. Young people thought CFS/ME caused depression because of the restrictions it placed on activities and their independence. They also described significant loss. Activities that they had previously enjoyed were no longer pleasurable due to both fatigue and anhedonia, and it was a reminder of their loss of the person they used to be. Different people found different treatment strategies helpful.

Several studies have shown that chronic illness in childhood has a substantial impact on functioning and can lead to a sense of loss and psychological distress (Surís, Parera, & Puig, 1996; Woodgate, 1998; Woodgate, Degner, & Yanofsky, 2003). Our findings, in a sample of young people with CFS/ME who are also experiencing psychological distress, are consistent with this mechanism. The young people in our study talked extensively about the impact of their illness on their lives, expressing both loss and sadness in relation to how their current situation compared with life before illness.

There is potential for overlap in symptomatology between depression and CFS/ME, but the young people in our study identified their symptoms of low mood and symptoms of CFS/ME as being separate. While most participants described their depression as following the development of CFS/ME, some felt that stress or depression occurred prior to or at the same time as development of CFS/ME symptoms. Our study therefore shows some similarities to previous prospective studies that showed that depression or psychiatric difficulties in young people can predate CFS/ME (Rimes et al., 2007; Ter Wolbeek, van Doornen, Kavelaars, Tersteeg-Kamperman, & Heijnen, 2011). It is also consistent with literature that illustrates how stressful life events (which may include being diagnosed with CFS/ME) contribute to the development of depression (Kendler, Karkowski, & Prescott, 1999).

Young people with CFS/ME but without depression have described previously how loss of friendships and school impacted on their quality of life (Fisher & Crawley, 2013). In our study, the

young people who were low in mood talked more extensively about loss, including loss of normal education, a social life and the experience of being a teenager. This theme of loss is consistent with cognitive theories of depression, which emphasise feelings of failure and loss as constituting what distinguishes depressive presentations from, for example, anxiety presentations in which feelings of danger and threat would be predominant (Clark, Beck, & Brown, 1989). Young people also clearly linked the functional impairments caused by CFS/ME to their mood because of the impact of their illness on what they could do behaviourally. This is consistent with behavioural theories of the development of depression (Lewinsohn & Graf, 1973), which postulate that a decrease in enjoyable activities and an increase in aversive experiences result in depression. This would be compounded by young people finding that previously enjoyable activities were no longer so pleasant because of fatigue and other symptoms, including post-exertional malaise.

Different young people found different treatment approaches to be helpful. Although CBT is an evidence-based therapy for both CFS/ME and depression, there are differences in the focus and sequence of interventions for each presentation, arising from the specific maintenance models for CFS/ME and depression. The cognitive behavioural model of CFS/ME (Browne & Chalder, 2006; Mackenzie & Wray, 2013) highlights how the symptoms of CFS/ME (e.g. fatigue, pain) cause individuals to avoid activities. Therefore, in CBT for CFS/ME, activity levels are stabilised in order to establish a consistent daily routine. This may initially require a reduction in some activities on some days. The focus of cognitive work is specifically on addressing unhelpful thoughts and beliefs about the illness, symptoms and activity (Browne & Chalder, 2006). In CBT for depression (Beck, 1979; Verduyn, Rogers, & Wood, 2009), withdrawal from activities that are pleasurable and/or give an individual a sense of achievement, combined with negative thinking patterns, are conceptualised as contributing to problem maintenance. Therefore, at the outset of treatment, there is a focus on scheduling and increasing such activities.

Cognitive work focuses on negative thoughts and beliefs related to shifts in mood, for example, a negative automatic thought that arises in response to attempting to do a specific task and not succeeding. As described by the participants of our study, there was no unitary approach that was experienced as helpful. It is therefore important to maintain a programme of individualised evidence-based treatment for young people, taking into account their preferences. Clinicians should be mindful of the possibility that treatment approaches for fatigue, which emphasise establishing a consistent and achievable amount of activity every day, conflict with approaches that are helpful for mood, such as engaging in activities that are enjoyable and/or give a sense of achievement. As young people concentrate on reducing activity to manage the CFS/ME, the paradoxical effect is that they do fewer enjoyable activities and are likely to have a sense that they have achieved less, which could compound their low mood. Treatment of paediatric CFS/ME should include screening for depression and strategies to prevent the development of depression. Further research needs to be done to develop treatment approaches that can be effective in the presence of both CFS/ME and depression, based on existing knowledge of the usefulness of selective serotonin re-uptake inhibitors (SSRIs) and CBT.

The strengths of our study are that qualitative methodology enabled us to explore the challenges and complexities of living with CFS/ME in detail, and the sample included a range of ages. Independent coding of the data by three researchers was undertaken to mitigate against bias, with good agreement between all three researchers. It is an additional strength of this study that the authors have different backgrounds (paediatrician, psychologist and clinical trainee), thereby offering different perspectives. One limitation is that all but one of the study participants was female, and the participants were at different stages in their recovery. This and the process of recruitment across a multidisciplinary team meant that we did not have a clear picture of reasons for declining to participate, or a reliable way of assessing possible selection bias. We were

unable to identify what treatment each participant had received, which may have affected their perspective on different management options. The self-report method of screening for depression is not as robust as using structured clinical interviews; therefore, some of those recruited may not have been diagnosed with depression had they had the structured clinical interview. Additionally, it is possible that some of the questions asked could have restricted the participants to a certain answer, and it is also possible that using a semi-structured topic guide may have limited our findings.

## Conclusion

Depression is a common problem in paediatric CFS/ME. We used qualitative methodology to explore why young people thought they had become depressed, whether their depression followed their CFS/ME, and their views on treatment. Most young people described their depression as being caused by the CFS/ME, and limited activity attenuated the positive effects of previously enjoyable activities. Young people described loss in a number of aspects of their lives, including education, family and social life. There was no unitary approach to treatment that young people found useful. Although the felt experience and perceived sequence of events reported by young people is their interpretation of what has happened, our study suggests that the impact of CFS/ME on quality of life contributes to the development of depression. The implication of this is that treatment of paediatric CFS/ME might be improved for some young people by incorporating individualised approaches to prevention and management of co-morbid depression.

## Key points

1. Approximately one-third of young people with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) have co-morbid depressive symptoms.
2. Young people tended to describe their experience of their depression as secondary to CFS/ME, and as resulting from the impact that CFS/ME had on their lives.
3. There was no unitary approach to management that young people found useful.
4. Clinicians should aim to prevent the development of depression and take an individualised approach to treatment, taking into account patient preference and current best practice guidelines.
5. Further research should focus on developing treatment approaches that can be effective in the presence of both CFS/ME and depression.

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## Declaration of conflicting interests

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## Appendix I

### Topic guide

*Why do young people with CFS/ME become depressed?*

**TOPIC GUIDE.** These questions will be used as prompts to ensure all important areas are covered.

Welcome, introduction, stress confidentiality. Discuss consent, sign form or check continues to be happy with consent.

1. Tell me about your CFS/ME
2. You score fairly highly on the HADS for low mood – can you tell me about that?

Prompts: what do they call it? Low mood or depression?

3. Discuss individual questions that rate high.

Prompts: is it school that makes you feel low? Friends? Boyfriend/girlfriend? Isolation? Lack of independence? Self-esteem? What's the worst thing about having CFS/ME?

4. Do you know which came first? The symptoms of fatigue or the symptoms of low mood/depression/feeling fed up?
5. Is there anything that could have been done that would have helped you or stopped the low mood/depression?
6. What would be helpful now?

Prompts: what are the treatments you're using? What do you think about them? Are there any other treatments that would be helpful?

7. Can you tell me any ways in which we could help support children and young people with CFS/ME?
8. Do you have anything else you would like to add? Do you have any questions?

Prompts: Was there anything that we didn't ask that we should have?