Published in final edited form as:
Clin Child Psychol Psychiatry. 2019 July 01; 24(3): 546–563. doi:10.1177/1359104519829796.

Illness perceptions in adolescents with chronic fatigue syndrome and other physical health conditions: Application of the common sense model

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Abstract

Background—The common sense model (CSM) proposes that illness perceptions guide coping and illness management, which subsequently affects outcomes. Chronic fatigue syndrome (CFS) is associated with severe functional impairment. CFS is distinct from other physical health conditions in that individuals can experience high levels of uncertainty, stigma and disbelief from others. This study aimed to compare illness perceptions in adolescents with CFS with other physical health conditions, using a cross-sectional, between-groups design.

Methods—Adolescents (aged 11–18) with CFS ($n = 49$), type 1 diabetes ($n = 52$) and juvenile idiopathic arthritis ($n = 42$) were recruited through National Health Service (NHS) clinics and online, and completed a series of questionnaires.

Results—Adolescents with CFS differed on the perceived consequences, timeline, personal control, treatment control, identity and understanding dimensions of illness perceptions. Except for identity, these dimensions were predicted by health condition even when accounting for age, gender, fatigue, physical functioning, anxiety and depression.

Conclusions—Results offer preliminary evidence for the applicability of the CSM in adolescents, with implications for supporting adolescents with physical health conditions. Results suggest that psychological interventions targeting perceived control, understanding and identity may have particular utility for adolescents with CFS.

Keywords

CFS; JIA; diabetes; illness representations; common sense model

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Declaration of Conflicting Interests
The author declared no potential conflicts of interest with respect to research authorship and for publication of this article.

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Introduction

Chronic fatigue syndrome (CFS) is characterised by prolonged, debilitating and unexplained fatigue, alongside other symptoms that can include cognitive, sleep and musculoskeletal problems (Fukuda et al., 1994; National Institute for Health and Care Excellence (NICE), 2007). The estimated prevalence of CFS in children and adolescents varies according to the diagnostic criteria used, ranging from around 0.1% to 2% (Brigden, Loades, Abbott, Bond-Kendall, & Crawley, 2017). The aetiology of CFS is not fully understood, but genetics, viral infection, immune and endocrine factors, stress, illness perceptions, psychiatric mechanisms and activity levels potentially contribute to its onset and/or maintenance in adolescents (Lievesley, Rimes, & Chalder, 2014). The functional impairment associated with CFS in adolescents is considerable. CFS has been identified as the biggest cause of long-term sickness from school (Crawley, Emond, & Sterne, 2011; Dowsett & Colby, 1997), with one study reporting an average of 1-year absence from school in adolescents with CFS (Rangel, Garralda, Levin, & Roberts, 2000). Adolescents with CFS also report functional impairment for carrying out activities at home (Garralda & Rangel, 2004) and impaired social functioning (Rangel et al., 2000).

As there is no definitive, objective test for its presence, CFS can only be diagnosed after exhaustive physical investigations and psychiatric assessment to exclude other potential causes of fatigue such as anaemia, hypothyroidism and primary depression (Afari & Buchwald, 2003; Devanur & Kerr, 2006). This can lead to certain psychosocial challenges specific to the illness experience in CFS. Qualitative analysis of interviews with adolescents with CFS identified a number of themes around uncertainty about the following: the future, the validity of CFS (experiencing disbelief and distrust by family, friends and teachers) and how to explain it to others (Fisher & Crawley, 2012). Several other studies have acknowledged the stigma associated with CFS, including a general ‘lack of permission’ from society to be ill in the absence of recognised disease (Nettleton, 2006). Trainee medics have been found to express negative attitudes towards individuals with CFS (Stenhoff, Sadreddini, Peters, & Wearden, 2015), and over a third of adult CFS patients report that a physician had failed to legitimise or acknowledge the reality of their experience (Lehman, Lehman, Hemphill, Mandel, & Cooper, 2002). Perceived stigma has been rated as higher in CFS than in other physical health conditions, including ‘medically unexplained’ conditions (Looper & Kirmayer, 2004). Thus, the illness experience in CFS is subjectively different to other physical health conditions.

The common sense model (CSM) of illness representation (Diefenbach & Leventhal, 1996; see Figure 1) proposes that individuals hold implicit cognitive and emotional perceptions of their illnesses (Hagger & Orbell, 2003). These perceptions are influenced by somatic experiences, social and cultural beliefs and knowledge derived from others, including professionals (Petrie & Weinman, 2006). Cognitive illness perceptions consist of illness identity (label given and symptoms attributed to the illness by the individual), perceived cause of the illness, timeline (how long the individual believes the illness will last), beliefs about controllability or curability and beliefs about the illness’ consequences. The Illness Perception Questionnaire (IPQ; Weinman, Petrie, Moss-Morris, & Horne, 1996), Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002) and Brief Illness

Perception Questionnaire (BIPQ; Broadbent, Petrie, Main, & Weinman, 2006) have all been devised to measure illness perceptions.

Illness perceptions are important because they guide coping responses and illness management, which in turn influence medical, psychological and behavioural outcomes (Petrie, Jago, & Devcich, 2007). Several studies have demonstrated that negative illness perceptions (e.g. beliefs about more severe illness consequences, more associated symptoms and longer timeline) are associated with increased disability, slower recovery and poorer quality of life, independent of initial medical severity of the condition (Hagger & Orbell, 2003; Petrie & Weinman, 2006). This finding has been supported in adults with a wide range of physical health conditions including chronic pain (Costa, Vale, Sobral, & Graca Pereira, 2016), chronic obstructive pulmonary disease (COPD) (Zoeckler, Kenn, Kuehl, Stenzel, & Rief, 2014), congenital heart disease (Schoormans et al., 2014), chronic kidney disease (Knowles, Swan, Salzberg, Castle, & Langham, 2014), asthma (Kaptein, Klok, Moss-Morris, & Brand, 2010), diabetes (Broadbent, Donkin, & Stroh, 2011) and CFS (Heijmans, 1998; Moss-Morris, Petrie, & Weinman, 1996). Consistent with the CSM, there is evidence that illness perceptions reported by CFS patients are distinct from illness perceptions in other physical health conditions, for example, greater identity and consequences perceptions, but more acute timelines have been found in adults with CFS compared to diabetes, chronic pain (Weinman et al., 1996) and rheumatoid arthritis, even when physical functioning is comparable (Moss-Morris & Chalder, 2003). The distinct illness experience in CFS means illness perceptions could hold potential for refining and improving interventions, and for reducing the distressing impact of CFS. Cognitive-behavioural therapy (CBT) is the treatment recommended by NICE (2007) for CFS. Illness perceptions are associated with adaptive outcomes in CFS (Heijmans, 1998; Moss-Morris et al., 1996), and it may be that CBT interventions need to target illness perceptions to be more effective (Wiborg, Knoop, Frank, & Bleijenberg, 2012). Notably, there has been little investigation of illness perceptions in adolescents, so the extent to which the CSM is applicable in adolescents with physical health conditions remains to be tested. One study focused on illness perceptions in young people with CFS (Gray & Rutter, 2007). Using the IPQ-R, young people were found to have identifiable perceptions of their CFS, which are linked to coping and outcomes. However, as no comparison group was included, it is unclear if these findings are unique to young people with CFS or generalisable across physical health conditions. Furthermore, generalisability of this particular study is limited. Specifically, the age of sample was predominantly young adults, and males were also underrepresented. Participants were recruited online via a self-help group, meaning that diagnoses were not verified. This method of recruitment also means that all participants were employing a particular coping strategy – again, limiting the generalisability of the findings. Furthermore, depression was not measured in this study, despite a high comorbidity; at least 30% of young people with CFS are believed to have probable depression (Bould, Collin, Lewis, Rimes, & Crawley, 2013; Loades, Rimes, Ali, Lievesley, & Chalder, 2018), and the tendency to make global, stable, internal attributions when depressed (Gladstone & Kaslow, 1995) could plausibly be linked to more negative illness perceptions.

Research in adults, including those with CFS, has provided support for the CSM, and illness perceptions appear to hold promise for improving interventions and alleviating some of the

distress that results from the illness experience in CFS. However, it is less clear if the CSM assumptions hold true in adolescent populations. Given the developmental differences between adults and adolescents, differences in power dynamics and routes into services, it is not sufficient to generalise research from adults.

This study aimed to compare illness perceptions across adolescents with CFS, juvenile idiopathic arthritis (JIA) and type 1 diabetes (T1D). JIA was chosen as a comparison group because it shares some similarities with CFS. Like CFS, it is idiopathic and there is an overlap in the nature of symptoms, with joint pain, stiffness and restricted movement featuring in both conditions (NICE, 2015b). However, JIA has observable physical markers that facilitate diagnosis, such as swelling and restricted movement in joints (Bailey, 2014). T1D was chosen as a control group, as it is a physical health condition with an identified physical cause and can be diagnosed with simple tests (NICE, 2015a). Both JIA and T1D are associated with less stigma than CFS. Fatigue and physical functioning were measured to test to what degree illness perceptions could be accounted for by these variables. Given the high prevalence of depression in CFS, and the possible relationship with cognitive perceptions, depression and anxiety were also measured. We expected that adolescents with CFS would be more fatigued than the other two groups, and have more depressive symptoms. We expected that levels of physical functioning would be comparable in JIA and CFS, with adolescents with T1D functioning better.

Based on the CSM and existing research in adults, we predicted that illness perceptions will differ in adolescents with CFS compared to JIA and T1D. More specifically, we predicted the following:

Hypothesis 1: Adolescents with CFS would report higher scores on identity, consequences and emotional responses subscales than adolescents with JIA and T1D.

Hypothesis 2: Adolescents with CFS would report a less chronic timeline and less personal control than adolescents with JIA and T1D.

Hypothesis 3: These differences in illness perceptions would remain when controlling for fatigue, physical functioning, depression and anxiety.

Method

Participants

CFS group—CFS participants were recruited from a specialist paediatric CFS team at the Royal United Hospital, Bath, as part of a larger study. Participants were recruited following diagnosis, but prior to receiving intervention from the service. CFS diagnoses were confirmed according to NICE (2007) criteria. The final CFS sample consisted of 49 participants aged 12–18 years ($M = 15.29$; $SD = 1.67$). See Figure 2 for distribution of participant ages.

JIA and T1D groups—JIA and T1D participants aged 11–17 years were recruited from Bristol Royal Hospital for Children and online. For clinic-recruited participants, diagnoses were confirmed by medical records prior to participation. Links to the online study

(including information sheets and consent forms) were posted in support groups on social media platforms and advertised online by national charities. Diagnoses were self-reported among these participants. Final samples consisted of 52 T1D participants (M = 14.58 years; SD = 1.85) and 42 JIA participants (M = 13.86 years; SD = 1.95). Of the 30 participants who completed the study online, 16 stated they were from United Kingdom; eight from the United States; two from Canada and one from Egypt, South Africa, Australia and Germany.

Procedure

Ethical approval was granted by Research Ethics Committees (CFS ref: 16/SW/0136; JIA/T1D ref: 16/WA/0378) and a University Ethics Committee. Clinic-recruited participants were invited to take part by health care professionals at outpatient clinic appointments. Participants aged less than 16 years were required to gain consent from a parent/carer. CFS participants completed paper questionnaires or electronically via REDCAP. JIA and T1D participants completed consent procedures and questionnaires electronically using the Qualtrics platform. In clinics, this was administered on iPads. Participants were left alone to complete the measures.

The final sample consisted of 143 participants. See Table 2 for descriptive characteristics of sample and Figure 3 for flow diagram of recruitment.

Measures

Demographics (age, gender and country of residence for participants recruited online) were collected via self-report questions. For CFS participants, medical comorbidities were recorded by health care professionals and screened for JIA and T1D. For JIA/T1D participants, physical health conditions were self-reported.

Internal consistency for measures and subscales was calculated using Cronbach's alphas (see Table 1).

Illness perceptions—BIPQ (Broadbent et al., 2006) is a nine-item measure of cognitive and emotional perceptions of illness – each measuring a different subscale. Eight items are rated on a 0–10 response scale: consequences (effect on life), timeline (expected duration), personal control (sense of control), treatment control (expected treatment effectiveness), identity (number and intensity of symptoms), concern, understanding and emotional response. The ninth item – cause – is open-ended, asking participants to list the three most important causal factors in their illness. The BIPQ has good to moderate concurrent validity with the IPQ-R – previously used in Gray and Rutter's (2007) study with adolescents with CFS – and has been found to have good validity and reliability in adults with a variety of illnesses (Broadbent et al., 2006). The BIPQ has been previously used in adolescents with different physical health conditions (e.g. McGrady et al., 2010; Michel, Taylor, Absolom, & Eiser, 2010), but formal psychometric properties have not been reported for this age group. Some studies which have used the BIPQ opt to produce total scores which represent the degree to which the illness is perceived as threatening (Broadbent et al., 2006), and others do not. We opted not to, as we felt that this could be overly reductionist and misleading, given our aims.

Anxiety and depression—Revised Children's Anxiety and Depression Scale (RCADS; Chorpita, Ebesutani, & Spence, 2011) is a 47-item questionnaire that measures separation anxiety, social phobia, generalised anxiety, panic, obsessive compulsive and depression. Items are rated on a four-point scale from 0 to 3. Total anxiety and depression raw scores were used in this study. The RCADS has been found to have favourable construct and factorial validity (Chorpita, Moffitt, & Gray, 2005).

Physical functioning—Physical functioning is measured using a 10-item physical functioning subscale of the 36-Item Short Form Health Survey (SF-36; Ware & Sherbourne, 1992). Items are rated on a three-point scale from 1 to 3 (Ware, Snow, Kosinski, & Gandek, 1993). Higher score indicates better physical functioning. High internal reliability of the subscale has been found in adults with CFS and convergent validity is also good (Buchwald, Pearlman, Umali, Schmaling, & Katon, 1996). The physical functioning subscale has previously been used in adolescents with CFS (e.g. Stulemeijer, de Jong, Fiselier, Hoogveld, & Bleijenberg, 2004) but has yet to be adequately validated.

Fatigue—The 11-item Chalder Fatigue Questionnaire (CFQ; Chalder et al., 1993) consists of two subscales: physical and mental fatigue. Items are rated on a four-point scale. The measure has been validated in both clinical and non-clinical adult samples (Cella & Chalder, 2010) and has been used extensively in research with adolescents with CFS (e.g. Bould et al., 2013; Crawley & Sterne, 2009). Scoring can take the form of a bimodal system, or a Likert-type system. In this study, Likert-type scoring was used, with each item scored 0–3, with items summed within each subscale. High internal consistency has been found for the scale (Cella & Chalder, 2010).

Data analysis

Exclusions and missing data—Two online participants were excluded from the analysis for having two of the physical health conditions of interest in this study. Twelve clinic-recruited participants were excluded for missing data (CFS = 9; T1D = 3), all with ⩾1 questionnaire missing. Where cases had ⩽5% of data missing (n = 6; all CFS), mean values were inputted for missing items (Roth, 1994). No items were missing from the BIPQ.

Power calculations—A priori power calculations were undertaken using G*power to establish necessary sample size. The BIPQ has not previously been used to compare illness perceptions in CFS and other conditions, so instead, effect size estimates were based on a study using the BIPQ to compare CFS participants with non-CFS fatigued participants (Cella & Chalder, 2010), who found significant between-group differences on several BIPQ variables. On the basis of their findings, with power set to 0.8, two-tailed tests with an alpha Bonferroni adjusted to .002 for multiple comparisons, a sample of 37 in each group would be large enough to detect differences on the consequence, timeline and identity variables.

Statistical analyses—All analyses were carried out using SPSS version 24. First, the three conditions (CFS, JIA and T1D) were compared on demographic characteristics and predictor variables. Data screening indicated that variables largely violated assumptions of normality and homogeneity of variance, so non-parametric tests were used. All comparisons

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were made using two-tailed tests, with Holm–Bonferroni corrected alphas. This controls the inflation of type 1 error rate, while maintaining power (Ludbrook, 1998). Pearson chi-square was used for gender and Kruskal–Wallis was used for continuous variables (age, physical fatigue, mental fatigue, physical functioning, depression and anxiety). The data file was then split by condition, and the same variables were compared across clinic-recruited and online-recruited participants. Chi-square was used for gender and Mann–Whitney for continuous variables.

Qualitative responses for the cause subscale of the BIPQ were coded by (a) psychological (including stress or overwork), (b) risk factors (including genetics or diet), (c) immune causes (including virus), (d) chance (including an accident or bad luck) or (e) physical over-activity. Blank or 'don't know' responses were not coded. As expected and observed counts were low within categories, percentages were compared. The eight continuous data BIPQ subscales were then compared across conditions using a series of Kruskal–Wallis tests.

Next, a series of multiple hierarchical regressions were conducted with BIPQ subscales as the dependent variables to establish whether the findings remained consistent when controlling for the predictor variables. As the outcome variables showed indicators of heteroscedasticity and non-normally distributed residuals, bootstrapping procedures were applied, with 1000 trials. Bootstrapping is a robust statistical technique that does not rely on these assumptions (Wright, London, & Field, 2011). Independent variables were entered in three blocks using the entry method. Gender and age were entered in the first block; physical fatigue, mental fatigue, physical functioning, depression score and anxiety score in the second block and condition in the third block. Condition was dummy coded using T1D as the reference group.

Results

Group comparison on predictor variables

The three conditions (CFS = 49, JIA = 42, T1D = 52) were compared across predictor variables. There was a significant effect of condition on gender ($\chi^2(2) = 7.78$, $p = .020$), age ($H(2) = 11.51$, $p = .003$), physical fatigue ($H(2) = 64.60$, $p < .001$), mental fatigue ($H(2) = 55.68$, $p < .001$), physical health ($H(2) = 37.54$, $p < .001$) and depression score ($H(2) = 20.04$, $p < .001$) (see Table 2). There was no significant effect of condition on anxiety score. The effect of condition on gender was followed up with inspection of standardised residuals, which indicated that there was a significantly higher proportion of females in JIA group than expected. Standardised residuals were not significant in CFS or T1D groups. Remaining significant differences were followed up with pairwise comparisons, using Bonferroni-adjusted p values. CFS participants were significantly older (mean rank: 86) than JIA participants (mean rank: 48; $p = .002$). There were no other differences in age. Physical fatigue was higher in CFS (mean rank: 110) than both JIA (mean rank: 57; $p < .001$) and T1D (mean rank: 48; $p < .001$). Mental fatigue was also significantly higher in CFS (mean rank: 107) than JIA (mean rank: 60; $p < .001$) and T1D (mean rank: 49; $p < .001$). Physical functioning was comparable across CFS (mean rank: 50) and JIA participants (mean rank: 64), with T1D participants (mean rank: 99) demonstrating significantly higher physical functioning than both ($p < .001$). Depression was significantly higher in CFS participants

(mean rank: 93) than JIA (mean rank: 62; $p = .001$) and T1D participants (mean rank: 60; $p < .001$).

No significant differences were found in predictor variables between online and clinic-recruited participants, except for higher physical functioning score in clinic-recruited JIA participants (mean rank: 25) than online-recruited JIA participants (mean rank: 16), indicating that those recruited from clinic had better overall health ($p = .033$). This did not remain significant when using the Holm–Bonferroni correction.

Group comparison on illness perceptions

Between-group comparisons on BIPQ subscales identified significant differences in consequences ($H(2) = 21.69$, $p < .001$), timeline ($H(2) = 56.20$, $p < .001$), personal control ($H(2) = 35.63$, $p < .001$), treatment control ($H(2) = 36.02$, $p < .001$), identity ($H(2) = 10.79$, $p = .005$) and understanding subscales ($H(2) = 16.64$, $p < .001$). There were no significant differences in concern or emotional response subscales. Pairwise comparisons indicated that illness consequences were rated as being greater in CFS participants (mean rank: 94) than in JIA (mean rank: 58; $p < .001$) or T1D participants (mean rank: 63; $p < .001$). T1D participants rated their condition as having a longer timeline (mean rank: 102) than JIA participants (mean rank: 69; $p < .001$) who in turn rated these items higher than CFS participants (mean rank: 43; $p = .005$). T1D participants also perceived more treatment control (mean rank: 96) than JIA participants (mean rank: 72; $p = .018$) and CFS participants (mean rank: 47; $p < .001$), with JIA perceiving more treatment control than CFS participants ($p = .009$). T1D participants rated themselves as having more personal control (mean rank: 98) than both JIA (mean rank: 65; $p < .001$) and CFS participants (mean rank: 50; $p < .001$), who did not significantly differ. CFS participants perceived experiencing more severe symptoms (mean rank: 87) than both JIA (mean rank: 61, $p = .007$) and T1D participants (mean rank: 66; $p = .29$), who did not differ from one another. Finally, understanding was significantly lower in CFS participants (mean rank: 53) than JIA (mean rank: 77; $p = .015$) and T1D participants (mean rank: 77; $p < .001$). See Table 3 for group comparisons.

Comparison of categorised responses for the cause subscale showed CFS participants were most likely to attribute cause of illness to psychological causes (39% of responses), followed by immune causes (34%). In contrast, JIA participants were most likely to attribute illness cause to risk factors (49%), followed by immune causes (27%). T1D participants perceived risk factors as the biggest cause (63%), followed by immune and chance factors (both 18%).

Thus, for hypothesis 1, we found that adolescents with CFS scored higher on the illness perception subscales of identity and consequences, than adolescents with JIA and T1D, as predicted. However, contrary to our prediction, they did not score higher on the emotional responses subscales. For hypothesis 2, we found that adolescents with CFS did report a less chronic timeline than adolescents with JIA and T1D, in line with expectations. Adolescents with CFS and adolescents with JIA reported less personal control than adolescents with T1D.

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Variance in illness perceptions explained by predictor variables

Bootstrapped multiple regressions demonstrated that, after accounting for age and gender, predictor variables (mental fatigue, physical fatigue, physical functioning, depression and anxiety) made a significant improvement to the amount of variance explained when consequences, timeline, personal control, treatment control, identity, understanding and emotional response were entered as the outcome variables. Entering condition at step 3 significantly improved the model for timeline, personal control and treatment control as outcome variables. JIA versus T1D was a significant predictor in the consequences dimension, and CFS versus T1D was a significant predictor in the understanding dimension. The final models at step 3 explained 41.1% of the total variance in the timeline dimension, 30.3% of variance in perceived personal control and 23.3% of variance in perceived treatment control (see Table 4).

Thus, we found evidence that the group differences in illness perceptions remained even when controlling for fatigue, physical functioning, depression and anxiety (hypothesis 3).

Discussion

This study investigated the assumption, based on the CSM, that illness perceptions differ across adolescents with different physical health conditions. We found evidence of significant differences between adolescents with CFS, JIA and T1D. As expected, the CFS participants reported significantly higher physical and mental fatigue than JIA and T1D participants. Comparable levels of physical functioning were found between CFS and JIA participants using the SF-36 subscale, while T1D participants reported higher physical functioning. Depression scores were higher among CFS participants compared to JIA and T1D. No significant differences were found in anxiety. Adolescents with CFS perceived greater consequences, greater identity, a less chronic timeline, less treatment control and less understanding of their condition than adolescents with JIA or T1D. Adolescents with CFS and JIA perceived less personal control over their illness than adolescents with T1D. With the exception of the identity subscale, these findings remained consistent when controlling for age, gender, fatigue, physical functioning, anxiety and depression.

The finding that illness perceptions differed across conditions supports the overall hypothesis that illness perceptions in adolescents with CFS are distinct from other physical health conditions. This is consistent with research with adults (Dickson, Toft, & O'Carroll, 2009; Moss-Morris & Chalder, 2003) and provides preliminary evidence for the validity of the CSM in adolescents with physical health conditions. As predicted, higher consequences and higher identity were reported in CFS participants – attesting to the severe functional impairment associated with CFS in adolescence (Crawley et al., 2011; Garralda & Rangel, 2004) and consistent with research with adults (Moss-Morris & Chalder, 2003; Wiborg et al., 2012). Previous studies have found that adults with CFS are more likely to attribute everyday symptoms to their condition compared to those with fracture or arthritis (Butler, Chalder, & Wessely, 2001; Moss-Morris & Chalder, 2003). It is possible that the poorly understood aetiology and uncertainty associated with CFS may lead to over-inclusion of symptom attribution. Furthermore, there were differences in illness perceptions between

T1D participants and JIA participants (e.g. personal control), further illuminating the differences in how illness is perceived between different health conditions.

In contrast to our prediction, no difference was found in the emotional response subscale across conditions. This is somewhat surprising given the uncertainty associated with CFS, participants' ratings of the severe impact on life and the higher depression scores present in participants with CFS. Given that CFS participants were most likely to attribute the cause of their illness to psychological factors, it is possible that adolescents with CFS are more likely to view CFS as a consequence of psychological difficulties, rather than the other way around. However, qualitative interviews with adolescents with CFS and depression found that most felt CFS predated depression (Taylor, Loades, Brigden, Collin, & Crawley, 2017). It is also possible the higher depression scores in CFS participants reflect the overlap in symptoms. Consistent with findings from previous studies (Bould et al., 2013; Loades et al., 2018), adolescents with CFS endorsed more symptoms of depression than the other two groups. The tendency to make global, stable, internal attributions when depressed (Gladstone & Kaslow, 1995) could partly explain the pattern of more negative illness perceptions. However, when levels of depression were controlled for in the regression analysis, we still found that there were significant group differences in illness perceptions, which suggests that depression symptoms do not fully explain the differences found. The relationship between mood, CFS and illness perceptions warrants further research.

The regression results suggest there is an aspect of having CFS, not accounted for by fatigue, depression or physical functioning, that is leading to lower perceived control. A possible explanation is that the lack of established aetiology of CFS, lack of clear medical treatment and the associated uncertainty may contribute to participants' diminished sense of control. According to the CSM, illness perceptions have implications for coping responses and illness management, as well as medical and psychological outcomes (Petrie et al., 2007). Meta-analyses of studies in adult populations have found that higher perceived control is consistently associated with better outcomes, such as greater physical functioning, role functioning and psychological well-being and lower distress and disease state (Hagger, Koch, Chatzisarantis, & Orbell, 2017; Hagger & Orbell, 2003). Higher perceived control is also associated with cognitive reappraisal, problem-focused coping and social support–seeking coping strategies, whereas lower perceived control is associated with avoidance. A systematic review of interventions targeting illness perceptions in adults found that perceived control most frequently shifted (Broadbent et al., 2015), suggesting that perceived control is amenable to change. Indeed, an increased sense of control has been hypothesised as being an important mediator for treatment outcomes in CBT for CFS in adults (Wiborg et al., 2012).

The perception of a less chronic timeline in CFS participants compared with JIA and T1D supports the hypothesis and is consistent with previous research with adults (Dickson et al., 2009; Moss-Morris & Chalder, 2003). This is suggestive of beliefs/hopes for recovery in adolescents with CFS, but as perceived control is low, this indicates that participants are attributing their anticipated recovery to factors outside of their control. Findings from wider literature on the relationship between perceived timeline and coping/outcomes are mixed. While some adult studies have found reported chronic timeline to be associated with worse

outcomes (Broadbent et al., 2015; Hagger & Orbell, 2003), Hagger et al. (2017) found some evidence that reported chronic timeline had an indirect effect of *higher* physical functioning, social functioning and well-being, with lower distress and disease state, mediated by problem-focused generic coping. It is possible that in some cases, perceiving a health condition as less chronic reduces motivation to engage in adjustment to the condition. Future research would benefit from examining these relationships specifically in adolescents with CFS.

Limitations

There are several limitations to this study, which should be accounted for in the interpretation of the findings. There were group differences in the method of recruitment, with CFS participants being recruited at their initial assessment at a specialist service, and JIA and T1D participants being recruited at initial assessment or follow-up at a specialist service. Furthermore, JIA and T1D participants recruited from clinics were a convenience sample, which limits generalisability. In addition, recruiting from specialist services means it is unclear to what extent findings generalise to participants treated in primary care, or those too unwell to access specialist services. It does, however, allow verification of diagnoses, whereas diagnoses in online-recruited participants were not clinically verified. Online participants may have also been from different cultural backgrounds to those recruited through specialist services. The finding of no differences between online and clinic-recruited participants is encouraging with regards to generalisability, but this will need to be further investigated in the future, and an exploration of cultural differences in subsequent studies would be valuable.

There was an overrepresentation of females in the T1D and JIA samples in comparison to other studies (Packham & Hall, 2002; Soltesz, Patterson, Dahlquist, & Group, 2007). In contrast, the gender distribution of the CFS sample was close to equal, whereas CFS is believed to affect females disproportionately by 3:1 (Lievesley et al., 2014). This raises questions regarding the representativeness of the samples.

The eligible age range for participants varied slightly across groups, which is partly due to differences in access between the specialist services. Groups were unmatched on demographic factors as we did not conduct a priori matching on these characteristics, although these were controlled for in the regression analyses. Duration of illness was not accounted for in this study, which could have differed across conditions. This is an important variable to consider in future research, as the CSM is a dynamic model, so illness duration may be associated with updated illness perceptions.

Although the measures used in this study have previously been used in research with adolescents, the CFQ and SF-36 physical functioning subscale have yet to be adequately validated in the populations in this study. Cronbach's alphas indicate good internal consistency, with the exception of mental fatigue, which was problematic in the JIA and T1D participants. The measures used were also exclusively self-report, and future studies may benefit from obtaining informant reports to complement self-report measures.

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Finally, it is important to remember the complexity of the relationship between physical and psychological variables when conducting studies in those with physical health conditions; according to the CSM, physical variables can be both illness outcomes and the internal stimuli that contribute to illness perceptions. Thus, there is not a simple linear causality when studying the role of psychological variables. It may also have been overly conservative to adjust for both fatigue and physical functioning, which are likely to be inter-related.

Implications

The preliminary support from this study for the validity of the CSM in adolescents suggests that illness perceptions differ between physical health conditions and are therefore important to consider as part of biopsychosocial assessment, formulation and treatment.

CBT is the evidence-based treatment recommended by NICE (2007) for adolescents with CFS; evidence shows that with specialist treatment, up to two-thirds of young people recover from CFS (Lloyd, Chalder, & Rimes, 2012; Nijhof, Bleijenberg, Uiterwaal, Kimpen, & van de Putte, 2012; Nijhof et al., 2013). However, the precise mechanisms of change in CBT for CFS are unclear; a better understanding of these mechanisms may improve the efficacy. Illness perceptions have previously been identified as an important target for CBT for adults with CFS (Wiborg et al., 2012). It may be that addressing illness perceptions more specifically in treatment could improve recovery rates. The lower perceived control found in CFS participants is likely to impact engagement with CBT. CBT requires collaborative engagement and a sense of self-efficacy (i.e. a sense of personal control); it is necessary that adolescents believe that the treatment being offered can support them to develop the skills required to bring about change (Stallard, 2005). This suggests that psychoeducation, socialisation to CBT as a form of treatment (and its effectiveness) and interventions aimed at improving personal control and self-efficacy may be important components to be delivered early in contact with services. Similarly, while the lower perceived understanding in CFS participants reflects a poorer medical understanding of the aetiology, this highlights the importance of giving service users the most up-to-date knowledge and research that we have available. The greater perceived identity evident in CFS participants may reflect over-attribution of symptoms to the condition, suggesting that interventions to reduce this could be helpful.

Future research

Future research would benefit from recruitment of larger and more culturally diverse samples from a range of settings to increase generalisability. Longitudinal designs would allow investigation of the relationship between illness perceptions, coping strategies and outcomes over time. Examining parental illness perceptions would also be important for understanding the developmental context. Intervention studies for adolescents with CFS should consider including a measure of illness perceptions to track changes and their relationship to other treatment outcomes.

Conclusion

This study found that adolescents with CFS differ in their illness perceptions compared to adolescents with other physical health conditions, thus providing initial evidence for the applicability of CSM in this population. In particular, CFS participants reported greater identity, lower perceived control, a less chronic timeline and less understanding of their illness. This is likely to have implications for the coping strategies used and the readiness to engage with evidence-based treatments. Interventions should consider explicitly targeting these perceptions to optimise outcomes. Future research should monitor the impact of intervention on illness perceptions.

Acknowledgements

The authors extend their thanks to all the young people who participated in this study, and to the health care professionals and research assistants who supported the study, particularly Dr Claire Semple, Dr Sangeeta Sawlani Ramos and Maddy Harris.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Dr Loades is funded by the National Institute for Health Research (Doctoral Research Fellowship, DRF-2016-09-021). This report is independent research. The views expressed in this publication are those of the authors(s) and not necessarily those of the National Health Service (NHS), the National Institute for Health Research or the Department of Health.

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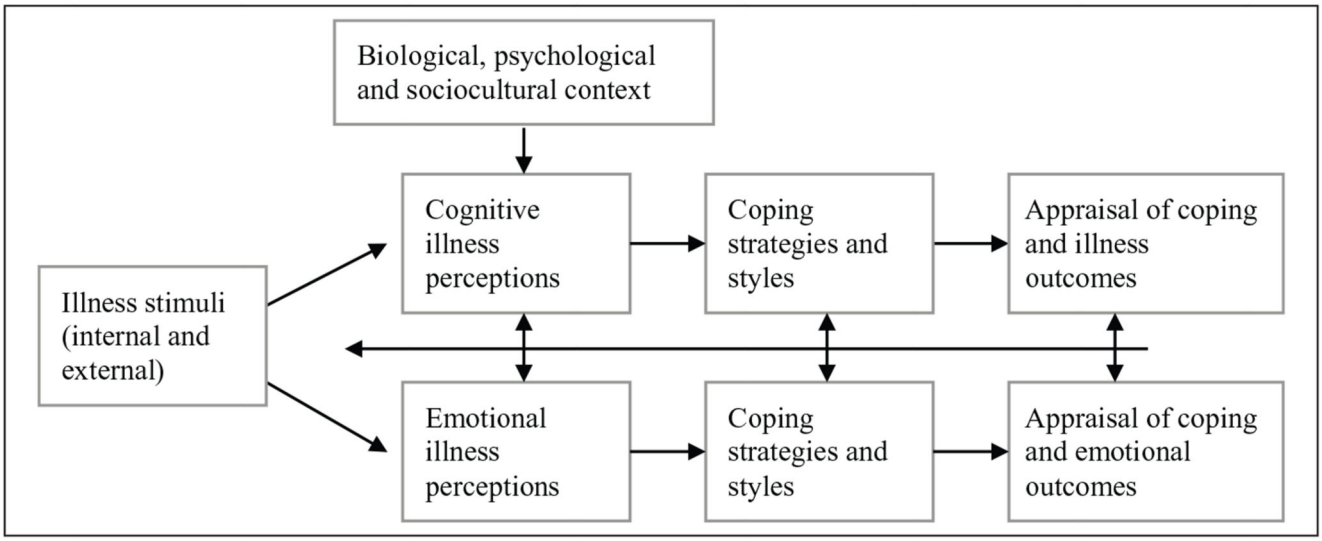

Figure 1.
The common sense model of illness representation. Adapted from Diefenbach and Leventhal (1996).

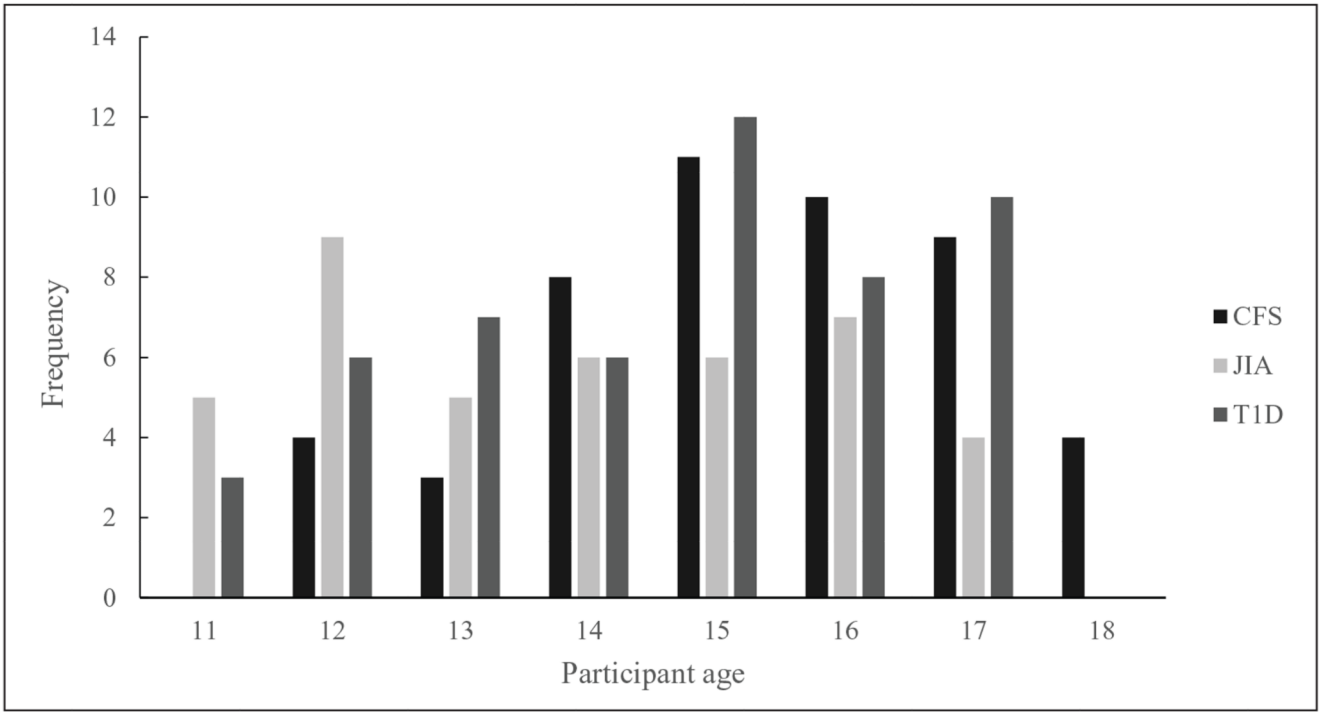

Figure 2.
Distribution of participant age across the three conditions.

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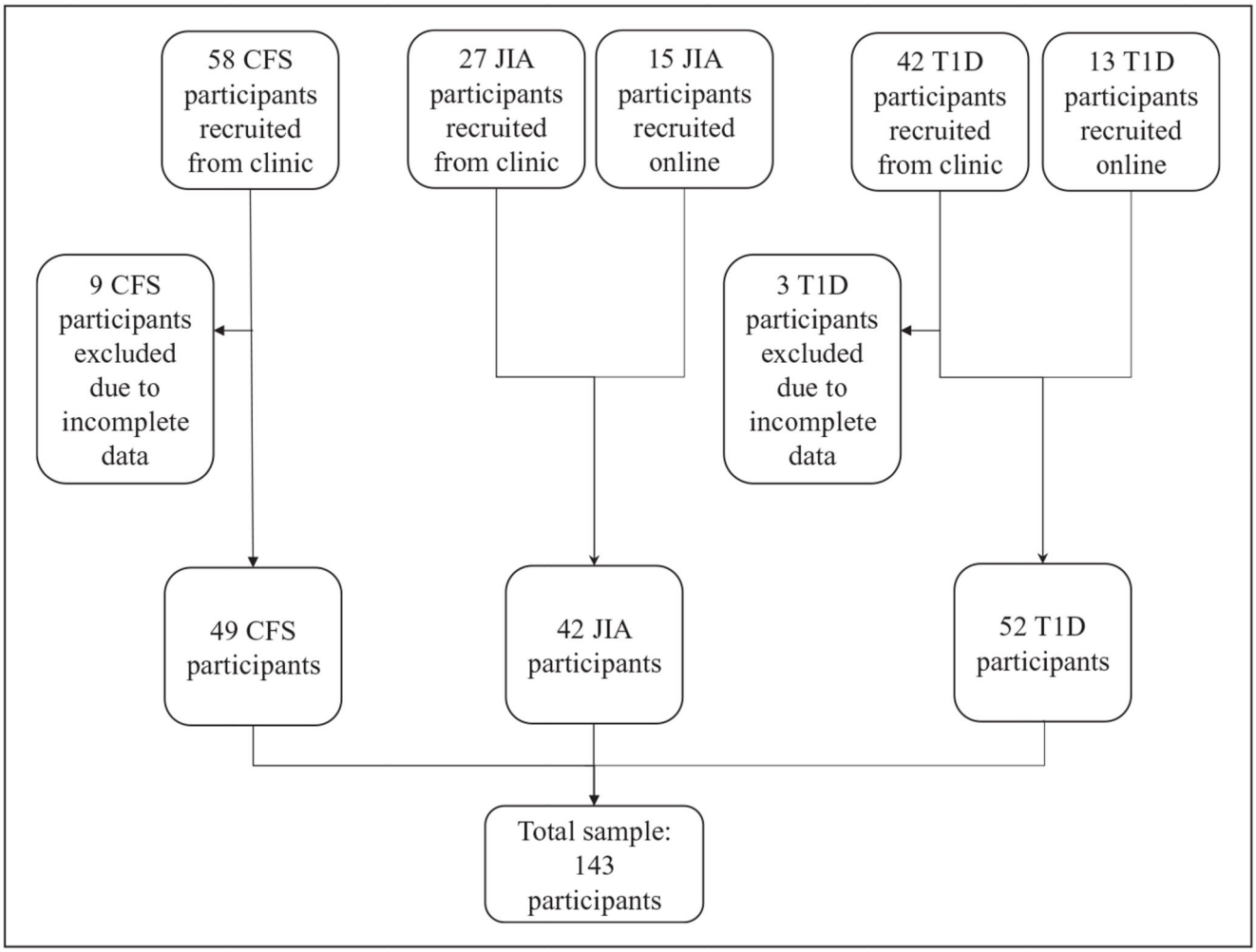

Figure 3.
Flowchart of participant recruitment.

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Table 1

Cronbach's alpha for subscales and overall measures.

	RCADS: Depression subscale	RCADS: Anxiety subscale	RCADS: Overall score	SF-36: Physical functioning subscale	CFQ: Mental fatigue subscale	CFQ: Physical fatigue subscale	CFQ: Overall score
CFS	.84	.95	.95	.92	.84	.87	.89
JIA	.90	.95	.96	.94	.53	.84	.82
T1D	.93	.97	.98	.90	.66	.92	.89

RCADS: Revised Children's Anxiety and Depression Scale; SF-36: 36-Item Short Form Health Survey; CFQ: Chalder Fatigue Questionnaire; CFS: chronic fatigue syndrome; JIA: juvenile idiopathic arthritis; T1D: type 1 diabetes.

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Table 2
Sample characteristics and between-condition comparisons.

	CFS (*n* = 49)		JIA (*n* = 42)		T1D (*n* = 52)		*p* value
	n	**%**	***n***	**%**	***n***	**%**	
Male	22	(45)	8	(19)	22	(42.3)	.020*
Female	27	(55)	34	(81)	30	(57.7)	
	M	*SD*	*M*	*SD*	*M*	*SD*	
Age	15.29[a]	(1.67)	13.86[b]	(1.95)	14.58[a, b]	(1.85)	.003*
Physical fatigue	17.39[a]	(3.27)	10.38[b]	(4.26)	9.12[b]	(4.91)	<.001*
Mental fatigue	8.37[a]	(2.48)	4.88[b]	(1.80)	4.31[b]	(2.22)	<.001*
Physical functioning	20.12[a]	(5.20)	21.98[a]	(5.86)	26.52[b]	(3.93)	<.001*
RCADS Depression	15.49[a]	(5.23)	10.52[b]	(5.99)	10.23[b]	(7.36)	<.001*
RCADS Anxiety	34.33[a]	(19.40)	30.88[a]	(18.12)	32.33[a]	(23.97)	.679

CFS: chronic fatigue syndrome; JIA: juvenile idiopathic arthritis; T1D: type 1 diabetes; RCADS: Revised Child Anxiety and Depression Scale; *SD*, standard deviation.
Shared superscripts denote no significant differences.
*Significant using Holm–Bonferroni adjusted *p* values.

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Table 3
Between-condition comparisons on BIPQ subscales.

	CFS (*n* = 49)		JIA (*n* = 42)		T1D (*n* = 52)		*p* value
	M	*SD*	*M*	*SD*	*M*	*SD*	
Consequences	7.71[a]	(1.61)	5.93[b]	(2.08)	6.15[b]	(2.15)	<.001*
Timeline	5.92[a]	(1.82)	7.50[b]	(2.58)	9.38[c]	(1.59)	<.001*
Personal control	3.10[a]	(2.17)	3.95[a]	(2.16)	5.87[b]	(1.96)	<.001*
Treatment control	5.20[a]	(2.30)	6.88[b]	(2.26)	8.15[c]	(2.36)	<.001*
Identity	7.35[a]	(1.84)	5.90[b]	(2.22)	6.04[b]	(2.36)	.005*
Concern	6.04[a]	(2.63)	5.74[a]	(2.43)	5.19[a]	(2.82)	.263
Understanding	6.65[a]	(2.00)	7.64[b]	(2.54)	8.19[b]	(1.93)	<.001*
Emotional response	6.53[a]	(2.82)	6.43[a]	(2.67)	6.04[a]	(2.92)	.679

BIPQ: Brief Illness Perception Questionnaire; CFS: chronic fatigue syndrome; JIA: juvenile idiopathic arthritis; T1D: type 1 diabetes.
Shared superscripts denote no significant differences.
*Significant using Holm–Bonferroni adjusted *p* value.

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Table 4

Results of hierarchical multiple regression analyses with BIPQ subscales as outcome variables.

Predictors	Consequences	Timeline	Personal control	Treatment control	Identity	Concern	Understanding	Emotional response
	***B* (*SE*)**	***B* (*SE*)**	***B* (*SE*)**	***B* (*SE*)**	***B* (*SE*)**	***B* (*SE*)**	***B* (*SE*)**	***B* (*SE*)**
Step 1								
Female gender	0.38 (0.31)	0.82 (0.32)*	−0.14 (0.39)	0.12 (0.44)	−0.02 (0.39)	0.22 (0.51)	0.54 (0.40)	0.87 (0.47)
Age	0.12 (0.08)	0.07 (0.09)	0.08 (0.10)	0.04 (0.11)	0.32 (0.11)**	0.23 (0.12)	0.11 (0.10)	0.14 (0.12)
R^2 change	.070**	.023	.007	.004	.104***	.050*	.016	.088**
Step 2								
Physical fatigue	0.53 (0.05)	−0.13 (0.06)*	−0.01 (0.06)	−0.01 (0.07)	0.02 (0.06)	0.04 (0.08)	0.06 (0.06)	0.08 (0.06)
Mental fatigue	0.08 (0.08)	0.15 (0.09)	0.11 (0.10)	0.05 (0.11)	−0.02 (0.09)	0.06 (0.14)	−0.10 (0.11)	−0.03 (0.11)
Physical functioning	−0.13 (0.03)***	−0.03 (0.04)	0.04 (0.04)	0.06 (0.03)	−0.12 (0.04)***	0.06 (0.05)	−0.03 (0.04)	0.05 (0.05)
Depression score	0.03 (0.04)	0.15 (0.04)***	−0.10 (0.05)*	−0.07 (0.05)	0.07 (0.04)	−0.01 (0.06)	−0.08 (0.07)	0.12 (0.05)*
Anxiety score	0.00 (0.01)	−0.02 (0.01)	0.00 (0.01)	0.00 (0.02)	−0.02 (0.01)	0.03 (0.02)	0.00 (0.02)	0.03 (0.02)*
R^2 change	.289***	.186***	.234***	.205***	.145***	.064	.094*	.231***
Step 3								
Condition								
T1D	Reference	Reference	Reference	Reference	Reference	Reference	Reference	Reference
JIA	−0.94 (0.42*)	−2.16 (0.47)***	−1.66 (0.47)***	−1.02 (0.49)*	−0.49 (0.48)	0.89 (0.59)	−0.72 (0.51)	0.43 (0.58)
CFS	−0.28 (0.53)	−3.97 (0.48)***	−2.41 (0.53)***	−2.39 (0.68)**	0.00 (0.48)	0.51 (0.78)	−1.43 (0.56)*	−0.55 (0.60)
R^2 change	.027	.239***	.107***	.073**	.007	.015	.037	.010
Overall adjusted R^2	.344	.411	.303	.233	.207	.070	.089	.284

BIPQ: Brief Illness Perception Questionnaire; T1D: type 1 diabetes; JIA: juvenile idiopathic arthritis; CFS: chronic fatigue syndrome.
All regression coefficients are from the final step in the analyses. Standard errors and significance values based on 1000 bootstrapped samples.
*$p < .05$; **$p < .01$; ***$p \leqslant .001$.